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Every Canadian Counts Coalition

229 Colonnade Road | Ottawa, Ontario K2E 7K3 | 613-447-8894 |

www.everycanadiancounts.com

Editorial

Disability Advocacy in Canada – a community divided

Recent years have shown great progress in addressing important issues for persons with disabilities largely as a consequence of renewed federal actions culminating the enshrining into legislation of the Accessibility Canada Act. This passage of this Act was important in two ways. First, it reflected a new activism on disability issues by the federal government after a roll back in engagement that began some 30 years ago. Secondly, and equally important, it represented the culmination of a brand of disability activism that began with the deinstitutionalization process in the 1970's but was propelled by the ideology of neo-liberalism, a doctrine which abhorred government and lauded market base solutions to social problems. Under this model 'community' was to replace government as the overseer of carer of last (and first) resort with government providing incentives for the community to take on this task.

Neoliberalism and the Community Movement

There is no doubt the community led movement has changed society's approach towards and understandings of persons with disabilities. It is reflected for example, in a changed discourse. We no longer speak of 'retarded', 'handicapped' or even disabled persons. It is persons with disabilities. In addition and in keeping with the market orientation of the broader neoliberal agenda which emphasized market relations and productive engagement with society, persons with disabilities were presented as people capable of contribution, and with that came the right to be employed, not a special basis, but on the same terms as anyone else. Indeed, if there is any agenda that has characterized the last decades of activism among the many organizations that represent persons with disabilities it has been the push for equitable access to employment. It was the driving force behind the Accessibility Agenda. The problem was seen to be not of the person with a disability, the individual, but of a society that was putting obstacles in the way of their participation. The turn of phrase was, 'People do not need fixing - society does.'

This neo-liberal perspective with respect to persons with disabilities rested on two fundamental guiding principles. One was that of the sovereign consumer. Persons with Disabilities were sovereign consumers like anyone else, and as such had the same right as anyone else to control of any resources that came their way. And with that came the right of choice. This notion has driven the individual funding (passport) agenda and was compatible with the individualized care model. Another important principle - already noted - was the presentation of individuals as productive members of society. Overarching both was neoliberalism's central thesis that an individual is valued and assessed in terms of their relationship to the market, i.e. as agents of supply and demand. Ideally under neoliberalism this market place was unburdened of government interference (deregulated) as much as possible where community replaced 'nanny state' government and its agents and agencies.

The Accessibility/Community building Agenda

There can be little argument as well that many of the elements of the neoliberal agenda were progressive. It placed the individual at the centre; it recognized the right of choice, and worked to change the image of persons with disabilities as contributing members of society. It also realigned programming for persons with disabilities in two major ways. The first was an emphasis on overcoming barriers to participation particularly with respect employment. Indeed, employment became the core message and focus of the activism that has been at the heart of the Accessibility Agenda. Deriving from this, the role of government in this framework was seen as an agency to help overcome barriers – not to oversee care. Care was not the issue as people ‘did not need fixing’.

The second programming emphasis that emerged related to ways governments could strengthen community support and especially support for families. In true neoliberal fashion this was accommodated with various tax incentives (RDSP, Disability Tax credit) or where transfer payments were involved, non-mediated direct to person funds (passport funding, CPP Disability benefit) to be used in the marketplace as consumer choice allowed. The assumption here was that Canada was a country was populated by wealth middle class families capable of providing the resources and support for the disabled family member where tax incentives would have a real impact.

A third programming emphasis and one which gave birth to the community movement in the early days was a preoccupation by many advocates with de-institutionalization of any form. It was not just the Regional Centres which housed hundreds, but group homes, and the government funded service agencies that supported them (including the sheltered workshops) which were viewed as violations of a persons right to live independently. They were seen as the antithesis of choice and reflected discrimination rooted in a prejudice that saw persons with disabilities as less valuable as contributing members of society.

The neoliberal agenda also promised one other thing: efficiencies. These efficiencies were born of its market orientation and consumer choice capability facilitated through the provision of competition. Then result was the fragmentation of the sector, with coalitions of advocacy and service being built around different disabilities (MS, Blind, Deaf, Spinal Bifida etc.) pursuing the same or different agendas, employment, housing, inclusion, training, accessibility, or combinations of often formed by parent’s groups but ultimately seeking government support. In this framework unified agenda setting was impossible as all the different groups competed for resources.

Through all this it has been the Accessibility/Community Agenda has been the dominant focus of activism and programmatic initiatives since the 1980’s. It has reached its Apex with the passage of the Government of Canada’s Accessibility Act in 2019. With that Act the federal government defined its role as a model employer of persons with disabilities in the hope that its example, coupled with facilitating instruments and programs, would encourage other levels of government, civil society and the private sector to adopt the same standards and practices.

But as anyone who it at all familiar with the landscape faced by persons with disabilities knows, we are far short of what is needed. Some, even the majority, benefit from the programming afforded by the accessibility approach, but many do and will not, or will do so only partially. And until those other needs are met, the community that is persons with disabilities will remain a community divided, and it will remain so unless we move on from the strict neoliberal market oriented straightjacket that has so focused (needlessly) disability related policy and programming in the last decades.

A Divided Constituency

The movement to community-based caregiving driven by the neoliberal ethic was revolutionary. But like all revolutions, there was a power structure to overcome. And there have been winners and losers in large part born of neoliberalism's inability to represent the interest of all persons with disabilities. After 50 years the neoliberal revolution has achieved only limited victory.

But first, who was the enemy? As already noted, it was governments. At the launch of the neo-liberal revolution it was symbolized by Nurse Ratchet from 'One Flew Over the Cuckoo's Nest,' the hard-hearted public health bureaucrat (hardly presented as a self-sacrificing nurse) in her role as a manager in a state-run institution. But as also noted above there was the assault on all the features of government programming of the day: sheltered workshops, Agencies charged with care and supports that received government funding, unions (driving up the cost of services when the money could be better directed to individuals) as well as any (even partial) defenders of the old 'ward of the state' system.



Who were the winners and losers? In what might be viewed as a harsh judgement, the winners were those typical of the neoliberal economic reform agenda – the lucky and the strong. When one examines the chief beneficiaries of the various Accessibility Acts, the singular achievement of the neoliberal era, it was those in the disability community that were well resourced and relatively privileged and/or capable. Expressed another way, society's adaptations were for persons with a disability who had the personal support they needed to engage in wider society and who were capable of adapting to the discipline of work at some level. And here lies the source of the great divide. The losers were those who did not have the personal service supports they needed and who were for any number of reasons incapable of working.

How did this group – the under supported and the less capable, become the losers? It was found in the slogan, 'people do not need fixing, society does'. This phrase denies non employment related personal need. It assumes personal needs are met. Indeed, the expression of need was discouraged as it was counter to the message of persons with disabilities being productive members of society. Neediness, if expressed, confused that message and perpetuated the image of dependency when independence was being preached. The result is that an entire constituency of persons with disabilities were denied a voice – the voice of needed supports that existed especially but not exclusively in the still state supported disability service agencies.



One group however has been able to bridge this divide and has made the call for 'needs' central to the discussion again. That is the Autism community. Autistic children are presented as often being capable, and even brilliant in some aspect of their lives (hence productive contributors) but cannot realize that potential without supports. But the need is great and governments have been resisting the calls.

In their activism the autism community has done the wider community of persons with disabilities a great service. They have pointed out a need for a new discourse not just for accessibility but for supports to help them with the challenges they face in day to day life.

A New Discourse in the Post COVID World

Post Accessibility Act, post Autism activism and now post COVID 19 it is time for a new discourse on disability issues. But before that new discourse can begin however some long held assumptions and predispositions need to be reassessed. They relate to: the ability of 'the community' to replace government: the role of agencies, and the embedding of persons with disabilities in market relationships.

With respect to the community replacing government as the care giver, this is a pipe dream. We noted that the assumption in the neoliberal model was that there was a middle class in Canada capable of looking after and supporting persons with disabilities if the right enabling conditions were made available. While it is true in many cases it is certainly not so for all, and furthermore it is likely to get less so looking ahead. Specifically, there are persons with disabilities who do not have families, or even families that don't care and don't want the responsibility of managing their care. Secondly, many middle-class families are under extreme financial pressure (highest debt loads in the OECD) and this is likely to be much more the case post-COVID. Thirdly, families are smaller and becoming more scattered with less ability to share the burden. Fourth, persons with disabilities are outliving their caregivers more frequently. Parents and caregivers are frantic and the state support is the only recourse many can foresee.

Agencies will not be going away. For some of the reasons noted above the demand for their services will likely grow. It is also worth recognizing the agencies themselves were the children of community activism. They were often founded by parents and caregivers. They are not denials of community they are reflections of them. In addition, they provide jobs, professional help and are often very creative institutions. They need to be strengthened. They have also embraced the positive features of neoliberalism: person centred programming and supports, embracing productive and meaningful engagement with society, and the right of choice.

Third, and singularly important, persons with disabilities are not defined by their relation to the market. They are not 'customers/consumers' or 'producers' but citizens and humans. They may or may not be 'productive' in the full economic sense of the term. But they are engaged and have a right to enjoy healthy, safe and secure lives as participating members of society, ideally enabled through equitable access to the broadest range of societal supports and opportunities.

Opportunities. Within this word lies the new discourse and the new programming. What is needed to maximize the opportunities for persons with disabilities however they might define them? It may be a need for a job, or a prosthesis, or therapy, or a personal care worker to help navigate the world. It is time to broaden the discourse and engage in related actions to not only provide accessibility but to address need.

The Opportunities Agenda

If a measure of society is in how it cares for its most vulnerable then Canada still has a long way to go to meet the needs and build opportunities for persons with disabilities. But if Canada is to meet its obligations under the CRPD it needs to up its game and reconceptualize the agenda. We will also need to find the means to do so, and as anyone familiar with the Every Canadian Counts Coalition agenda the most efficient funding mechanism to do so is through a national disability insurance program.

Current Affairs

The Economy Post-COVID: New Directions for the Federal Government

It is not enough to win a war. You must also win the peace that comes after. For Canada it will be, post COVID 19, winning the hearts and minds of a traumatized population that never wants so many of its populace to bear such costs nor feel so vulnerable again.

We have been here before. Following the Second World War a devastated Europe found new life and energy through the building of a new social contract and the implementation of a plan for reconstruction – the Marshall Plan.



The Marshall Plan was a large-scale economic rescue program. It addressed weaknesses in the economy and in combination with welfare measures resulted in the economic revival of Europe. It is the sort of thing that is needed now.

What would such a rescue plan look like Post-COVID? The weaknesses and vulnerabilities that emerged from the society wide lockdown are suggestive of the focus and kinds of measures needed. These weaknesses were most manifest in seniors care, underpaid and precarious work forces, the thin margins of economic sustainability for millions and the vulnerability to key supplies like medical equipment and some food sources, and All of this within a backdrop of climate change and a shattered global economy of massively high unemployment.

What does all this indicate or suggest by way of a road map as we try to move forward. At an aggregate level it signals a rebalancing of the public and private spheres. This will need to occur on the basis of principles and initiatives that will need to address the most pressing issues that have emerged

Among the principles would be:

An Economy of Fair Prices and not Cheapest Price: The global search for the cheapest price and production costs has led to a race to the bottom and is the single biggest source of the hollowing out of the middle class in the developed world. A fair price on the other hand would recognize labour an environmental standard as a component of the price regime. Long been advocated for, it would address simultaneously climate change and poverty and precarious work issues.

The Market is not always the Answer: The era of ‘let the market decide’ is over. Public policy needs to be broadened and strengthened with a focus on building resiliency and redundancy (not enabled by least cost approaches to system building). Privatization needs to be rolled back and the role of non-profit and public goods strengthened and restored on a fair price basis.

The Welfare/opportunity System must be Strengthened. Well being, access to education and information, should not be determined by private wealth. As jobs become 'project/piece work based' universal social safety nets are more and not less important. Guaranteed annual income? Certainly, with other measures, is a consideration.

Taxation is not a dirty word: Overhaul of the tax system is necessary addressing matters of leakage and unfairness but also recognizing that state revenues are inadequate. Social policy through tax exemptions have long fallen short of meeting the needs of the marginalized and vulnerable as a start. If noting else the epidemic has restored the indispensable role of the state. It is the job of the King after all (the state) to keep the granaries full. But it needs to be properly financed and not continuously handcuffed.

These principles can become the philosophical and ethical anchor to specific policy initiatives that would entrench not only this ethic, but provide widespread and energizing benefits to the economy of the future.

A Revised Globalism: Many challenges remain global in nature, but the globalization based on market efficiencies is not up to the job of what is needed. It cannot deal with pandemics. It is not dealing with climate change. It is not dealing with displaced populations. It is all about trade and that has to stop or at least given a more reasonable place in our priorities.

The Internet as Public Utility: The lock down resulting from the epidemic has adrenalized the on-line world and has shown its importance to the functioning of any future economy and society. Differential access entrenches inequality and is not acceptable. It is one of the public policy challenges of the time and needs to be in the public domain

A National Disability Insurance Program. Persons with disabilities have always been treated differently. Seen as welfare cases they were never part of the Medicare system committed to getting people 'back on their feet' as best it could. This needs to change. One pioneering program in Australia, the National Disability Insurance Scheme provided not only an anti-poverty stimulus, and needed social and other supports but upon its roll out provided more new net jobs than any other sector in Australia in 2018 2109. A much-needed initiative post-COVID.

The COVID -19 epidemic has revealed the fragility of our economies and societies. The entire system is working on tight margins in the name of efficiency. Glittering communications technology enabled us to communicate despite lockdown while our food supplies crumbled. Workers who had been mistreated, exploited and taken for granted now became indispensable. We had lost sight of what mattered.

Much thought will need to go into rebuilding the post-COVID world. If nothing else is clear we cannot afford to go back. But we have been here before and with very creative and progressive results. It is time to do it again.

What Next?

The Research Agenda

The focus of Every Canadian Counts Coalition activity currently is the promotion of a research agenda which would examine the cost and benefits of a national disability insurance program/. Every Canadian Counts Coalition is confident that not only will such a program provide a higher level and quality of supports for persons with disabilities but it will also be of benefit to the economy. It will do so by: generating employment; stimulating creativity and innovation and relieving stress on families especially as many care givers will be in a position to return to work. In Australia the program had especially beneficial effects in remote Aboriginal communities where services were improved and jobs created.

To reach our objective of a funded research project by the federal government, the Every Canadian Counts Coalition has been in active contact with the Human Resource and Finance Committees of the House of Commons as represented by our submission "Alleviating Poverty Among Canadians Living with Chronic Disabilities" which is available on our website at <http://everycanadiancounts.com/wp-content/uploads/2017/12/ECC%20Submission%20to%20HUMA%20PRS%20-%20FINAL.pdf>

What You Can Do

The following are members of the Human Resources Committee of Parliament

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Please contact them and relate to them your support for a national disability insurance program that will not only help to relieve poverty among persons with disabilities but will provide them with the support services they need while delivering an economic stimulus for Canada.