



The Autism Opportunity

NEEDS AND SOLUTIONS FOR CANADIANS WITH DISABILITIES

Photo courtesy of Kelly Brothers Productions

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The federal and provincial governments have announced their intention to work together to develop a national dementia strategy in response to the growing awareness of the rising numbers of Canadians who will live with the condition. The time is opportune for the federal government to extend the scope of the strategy to include neurodevelopmental disabilities (NDD). In particular, adults with Autism Spectrum Disorder (ASD), one of the most prevalent and costly NDD in Canada, have unmet needs and large gaps in services. Unlike these conditions, with the onset later in life, ASD needs are lifelong. Federal initiatives on employment are a good start but a comprehensive strategy that will address housing, caregiver burden, income supports and health issues is still needed.

Autism Spectrum Disorder is a neurodevelopmental condition that is characterized by lifelong impairments in social relationships and communication, and repetitive, rigid behaviours. Most individuals require some level of lifelong support but face an adult support system that is struggling to meet current needs.

Autism is one of society's most costly neurodevelopmental conditions. Based on a 2006 study from the US, by M.L. Ganz, the net present value at birth of the incremental costs of supporting the ASD population over its neurotypical peers in Canada can be estimated to be \$3.4 billion for each annual birth cohort. Cost categories included in this calculation were

for the increased use of health care services, special equipment, home care support, special education, and respite. The most substantial costs amounts are in the area of adult care and lost employment opportunities of both the individual with autism and his/her parent.

Currently, most resources and sup-

ports are directed towards children and adolescents in the first quarter of their lives, but for adults and their families there is a meager fragmented system to support the remaining three quarters of their lives. As the person with autism turns 18, they face a support cliff in most provinces. Moreover, there is a disconnect in most provinces between the childhood system of care and the adult system of care. Many families are left feeling they have to start over again and the valuable developmental and functional gains from costly childhood interventions are not furthered. At age 18, the day-time activities and structured learning provided through the education system often come to an end and adults with few employment options, post-secondary opportunities or appropriate day programs face a difficult void.

Federal initiatives like the programs and services offered by Employment Social Development Canada (ESDC), in particular the Opportunities Fund are important initial steps in filling this void. Community Works Canada, together with Ready Willing and Able, will reach close to 1,000 individuals with ASD and employers to begin better pathways to employment.

In some provinces individuals with NDD at age 18 will be excluded from future government supports solely based on their IQ score being over the IQ cutoff, even when they lack skills for full independence. Adults with ASD and other NDD need to have comprehensive transition assessments that take into account their employment skills beyond IQ. Unique provincial programs, like Meticulon, a successful IT placement company funded by ESDC and the Sinneave Family Foundation is using MIND MAPS to help determine an individual's strengths and weaknesses prior to job placement.

These programs are a start. Still, adult outcomes across provinces and shown in the research literature are poor. For those with IQ in the normal range, only a minority live independently. Canadians with ASD, along with other neurodevelopmental conditions, have extremely low labour

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force participation. Full-time employment that results in a living wage is rare and most adults with ASD are dependent on income derived from combinations of partial work, family support and public support via income support programs. Most live with their aging parents. Many need assistance with daily living skills, like bill paying and cooking, while others require full-time supports to manage the most basic of needs. There are a variety of effective programs to teach these skills, but they are not widely available in Canada.

Anxiety, depression, epilepsy, and schizophrenia are significantly more prevalent in this population. Challenging behaviours, when present, add another layer of difficulty. Aggressive behaviour can be unmanageable for families and lead to decreased community integration and a poorer quality of life for individuals. The child and youth-based service system that offered dollars for respite to families and specialized services like behavioural psychologists and speech therapists, are often less available when the person with NDD turns 18. This situation occurs in the context of an eventual decreased support capacity of the family due to parental aging and possible illness. Physical fitness programs may help to decrease anxiety and behavioural problems. Recreation, specifically, moderate to high intensity exercise programs, known to decrease mental health disorders, is available to only five per cent of Canadians with disability. The Abilities Centre, founded by the late Jim Flaherty, is pioneering programs to address this need together with Olympian Hayley Wickenheiser.

Quality housing options are not readily accessible despite the growing need for housing and support services. In a National Housing and Residential Supports



Hayley Wickenheiser, a University of Calgary Masters student, began a high intensity "Stepping Out" program for adults with autism. Photo courtesy of Kelly Brothers Productions

Survey of caregivers for those with ASD, it was found that the ideal living situation for many individuals with ASD was living at home with their family, with a minority reporting that a group home or their own home was the preferred option. Living at home however, is only viable in the context of a strong system of community services and available respite options.

Financial and emotional lifelong burden for caregivers is high. The time costs of caring for children with severe disabilities compared to those without disabilities is significant and does not decrease with advancing age. In a recent study by Zuleyha Cidav and colleagues, average earnings in families with children with ASD, for instance, are 28 per cent lower than in families whose children do not have health limitations and 21 per cent less than families with children with other health limitations. Consider, for example, the costs for caregiving time alone for the most severe adults, who require 24-hour support. This level of support equates to \$158,000 per year, or \$5.5 million over the lifetime. Loss of employment opportunities and out-of-pocket expenses put families under excessive financial burden. Lifelong caregiving is linked to chronic stress which

WHAT POLICY SOLUTIONS WILL HELP?

- 1) **Include Neurodevelopmental Disability Issues in the Current Discussions on Long-Term Care:** A long-term care strategy is on the agenda of government for the aging population, in particular for those who live with varying NDD such as ASD, the needs for some are similar to those living with dementia and Alzheimer's disease. We recognize that there is much variability in the level of support needs of persons with ASD given the vast range of ASD manifestations. Yet, proactive planning for this range of needs offers potential solutions for individuals touched by the range of these neuro-affected conditions, including ASD. This offers an opportunity to broaden the discussion to include those with NDD. Housing options that are available for a spectrum condition regardless of which province one lives in are needed. Research and reports exist, the need is apparent; take this opportunity to also help this growing demographic and their aging families.
- 2) **Stimulate the Market of Qualified Caregivers:** Finding and paying for qualified staff to provide respite for short and longer term periods is difficult. The turnover rate of staff serving adults with developmental disabilities is 50 per cent. With the difficulties recruiting and retaining qualified staff, and a growing number of adults in need of support, a critical challenge in delivering effective services exists. Stimulating the market to increase the availability of qualified workers who can help fill roles needed; in-home support, out-of-home respite workers, group-home ASD trained staff and life-skill coaches, are only a few examples of the support-care positions needed.
- 3) **Income Supports:** Many people living with neurodevelopmental conditions rely on the combination of income assistance, family supports and low wages from partial or low level employment. Income assistance programs are offered in varying amounts across provinces to those with severe disability. A feasible step to addressing some of the income needs would be to remove the age test for eligibility for the federal Old Age Security and Guaranteed Income Supplement pension benefits for persons living with an NDD.
- 4) **An Insurance Model to Finance Lifelong Support:** Alternative models to finance care are available. In the province of Quebec, the government is proposing autonomy insurance as an initiative to address the long-term care needs of the aging population and those with disability. Autonomy insurance is an innovative social project intended to address the increasing demands on services for long-term care. If implemented, autonomy insurance would be available to all adults with disability based on their profile of needs and will provide the appropriate level and type of service needed.
- 5) **A National ASD/NDD Platform:** The lifespan needs for a spectrum condition are complex, varied and intertwined. For instance, enhancing employment outcomes constitutes one component of a cross-ministerial strategy needed to deal with the gaps that exist. Provinces still vary considerably on what is available. The recent employment initiatives by the federal government will seek to develop best practice in employment and are expected to make a profound difference for adults. A strategy that also addresses income supports, quality housing options, brain health and caregiver burden is needed. This needs to be supported by robust data collection and analysis at a national level to monitor progress and implement program refinements based on evaluation findings, particularly as this new system of care scales up.
- 6) **Broaden the Active Canada 2020 Framework:** There is a need to specifically target individuals with disabilities to receive at least twice weekly moderate to high intensity exercise as part of their recreation and activity routine. We suggest that caregivers should be provided with similar opportunities.

often leads to compromised mental and physical health of the caregiver.

In many provinces, governments share some of the costs for individuals with high needs but when dollar amounts do not cover full costs, or when—regardless of costs—qualified and available support people cannot be found, then the burden of lifelong care reverts to the aging or other family. These issues were expressed in the 2007 report, *Pay Now or Pay Later: Autism Families in Crisis*, where the Standing Senate Committee on Social Affairs and Technology heard from parents and advocacy groups about the emotional and financial stresses that families face.

We applaud the efforts over the past decade in the areas of early intervention programs for the preschool years and the recent efforts on employment initiatives. The federal government's commitment to improve employ-

ment outcomes through Community Works Canada and Ready, Willing and Able programs, designed to prepare and support youth for employment, will help. These initiatives are elements that move towards enhanced quality of life, but even with better employment outcomes; in-kind supports for caregiving, housing options, income supports, and fitness initiatives still need to be addressed.

With the recent announcement by Health Minister Rona Ambrose that the federal and provincial governments will work together to develop a national dementia strategy, the best opportunity to address the needs of the large and growing population of adults with ASD is to emulate the dementia strategy to address ASD and other NDDs. Let's build on the federal momentum seen on employment issues and address the remaining lifespan gaps to make Canada a world leader in the implementation

of a comprehensive sustainable neurodevelopmental strategy. **P**

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