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Paying Now: Recommendations for the Development of Canada's National Autism Strategy

Connor Hasegawa

School of Public Policy, Simon Fraser University

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Introduction

A decade ago, the Senate Committee on Social Affairs, Science and Technology published *Pay Now or Pay Later: Autism Families in Crisis*, a report which examined the state of funding for Autism spectrum disorder (ASD) treatment across the country. The report identified major issues with Canada's current approach to the treatment of ASD, including issues of access to and wait times for services, stresses on families, and insufficient disability supports.¹ The report concluded with several recommendations, the most significant of which was that the federal government work with the provinces and territories to establish a comprehensive National ASD Strategy. The consequences of not paying for services and interventions, the report argued, would be paying more for welfare, social services and institutional care in the future.² Despite these warnings, the lack of national strategy to address ASD continues. Its absence has not gone unnoticed, as politicians, advocacy groups and experts continue to call for development of a national strategy.^{3 4 5}

Background

The lack of a national strategy to address autism has only grown more unacceptable since the publication of the senate report. At the time of publication, the rate of ASD in Canada was often cited as 1 in 166.⁶ Current studies suggest that the rate of ASD diagnoses is now much higher, with the U.S. Centers for Disease Control and Prevention estimating that roughly 1 in 68 American children fall somewhere on the autism spectrum.⁷ Service shortfalls have also grown since the publication of the senate report. In Ontario for example, between 2005 and 2015, the number of children on the applied behavioural analysis (ABA) intervention waitlist grew from 2,784 to 13,966.⁸ This growth in diagnoses and service shortfalls suggest that ASD poses an even greater challenge to Canadians now than it did a decade ago, when it was first identified by the Senate as a crisis.

A national strategy is also needed to avoid further litigation over ASD funding. Canada has already witnessed several significant court decisions regarding the duty of government to fund ASD interventions, including 11 cases in various provinces between 2003 and 2004. While

¹ The Standing Senate Committee on Social Affairs, Science and Technology. "Pay Now or Pay Later: Autism Families in Crisis." Government of Canada, March 2007. 7-9.

² Ibid., 13-19.

³ Senate of Canada. "Senate of Canada - Senators Request a Meeting with the Prime Minister and Minister of Health on Autism." Senate of Canada, November 1, 2017. <https://sencanada.ca/en/sencaplus/news/senators-request-a-meeting-with-the-prime-minister-and-minister-of-health-on-autism/>.

⁴ Canadian Autism Partnership Project, "Project Objectives." Accessed November 29, 2017. <http://www.cappproject.ca/index.php/en/about-cappproject/project-objectives>.

⁵ Autism Canada. "Autism Canada Annual Report 2013," 2013. 7.

⁶ Standing Senate Committee on Social Affairs, Science and Technology, "Pay Now or Pay Later," 4.

⁷ Autism Speaks Canada "What Is Autism - Autism Speaks Canada." Accessed November 29, 2017. <https://www.autismspeaks.ca/about-autism/what-is-autism/>.

⁸ "Wait Lists Growing for Autism Treatment in Ontario - Toronto - CBC News." Accessed November 29, 2017. <http://www.cbc.ca/news/canada/toronto/wait-list-autism-ontario-1.3303056>.

these cases established that governments were not obligated to fund behavioural interventions as a medically necessary service, the failure to adequately serve persons with ASD still leaves governments vulnerable to litigation. Examples of this can be seen in Ontario, where the provincial government is currently facing lawsuits regarding the years-long waitlist for ASD services and the lack of supportive housing for adults with developmental disorders.⁹ ¹⁰ Federal leadership and support for ASD would help to reduce the funding and access issues found in most provinces, which would reduce the likelihood of costly litigation and court-driven policies.

A national ASD strategy is also necessary to ensure all Canadians with ASD have access to quality services, regardless of where they reside. The current system of ASD has also resulted in a great deal of variation between provinces and territories in how services are delivered to children and families. In some provinces, such as Ontario and Nova Scotia, public intervention services are provided to children with ASD, while in others, such as BC and Alberta, families receive individualized funding to subsidize the cost of private interventions. The one thing that is consistent across all provinces is the necessity for parents to cover funding shortfalls.¹¹ The variations in service delivery, funding, and waitlists have created a situation where not all Canadians have equal access to services. In some instances, the inequity of access has resulted in medical migration, as families are forced to relocate to another province to access services. A national ASD strategy could help reduce provincial disparities and promote equal access for all Canadians living with ASD.

Recommendations

Assisting Canadians living with ASD is a complex task, as there is large variation in how the disorder affects individuals. Different individuals will require different supports depending on a variety of factors including the nature of their disorder, their socioeconomic status, where they live, and how ASD is viewed by themselves and their families. This makes the development of a single policy to assist every Canadian living with ASD an impossible task. Canada's approach to a national ASD strategy should instead include an array of policies which target areas where individuals with ASD typically need support. The following is a list of the four policies which should be at the core of national ASD strategy.

Recommendation 1: Increase access to interventions through targeted ASD funding to the provinces

⁹ "\$110M Lawsuit Targets Ontario Wait Lists for Developmentally Delayed Adults," Toronto Star, April 23, 2017, <https://www.thestar.com/news/gta/2017/04/23/110m-lawsuit-targets-ontario-wait-lists-for-developmentally-delayed-adults.html>

¹⁰ "Parents, MPPs Rally for Funding for Developmentally Disabled Adults - Windsor - CBC News." Accessed November 29, 2017. <http://www.cbc.ca/news/canada/windsor/parents-mpps-rally-for-funding-for-developmentally-disabled-adults-1.4108787>.

¹¹ Shepherd, Cody A., and Charlotte Waddell. "A Qualitative Study of Autism Policy in Canada: Seeking Consensus on Children's Services." *Journal of Autism and Developmental Disorders* 45, no. 11 (November 2015): 3551.

While the federal government may not have direct control over the provision of ASD services, its role as funder of the health system allows it to influence where provincial investments are made. Over the past year, the federal government has reached health funding agreements with several provinces that include targeted funding for home care and mental health initiatives. Under these agreements, provinces are required to lay out plans as to how targeted funds will be spent, and to develop indicators and mechanisms for reporting to citizens.^{12 13} Similar funding arrangements should be made for ASD services to ensure that Canadians living with ASD have access to high quality services regardless of where they reside. Indicators to measure the performance of targeted funds should include waitlist reduction, out-of-pocket expenses for families, and access to diagnosis and intervention.

Recommendation 2: Implement a catastrophic therapy insurance program

In 2002, the Senate released a report entitled *The Health of Canadians – The Federal Role*. In this report were several recommendations regarding the federal government's role in health care reform, including a recommendation for the introduction of a program to protect Canadians against catastrophic prescription drug expenses.¹⁴ This was to be accomplished by establishing a cap on the drug expenses that individuals could incur, with 90% of all expenses beyond the cap paid for by the federal government and the remaining 10% paid for by the provinces/territories. This type of funding arrangement was also discussed in the Senate's *Pay Now or Pay Later* report in 2007.¹⁵ Given the high cost of therapy for individuals with ASD, this type of cost sharing program could be extremely effective in protecting families from catastrophic therapy expenses and ensuring access to services.

Recommendation 3: Ensure federal National Housing Strategy supports individuals living with ASD

In *Budget 2017*, the federal government announced its intention to launch a National Housing Strategy, which included funds for supporting vulnerable citizens and measures to make housing more affordable for persons with disabilities.¹⁶ While this investment is a step in the right direction, a recent announcement of the strategy's details shows that it is inadequate to address the current and future housing needs of Canadians with ASD. Funding from the strategy is estimated to create another 2,400 affordable housing units for people with developmental

¹² Health Canada. "Canada Reaches Health Funding Agreement with British Columbia." News releases. February 17, 2017. https://www.canada.ca/en/health-canada/news/2017/02/canada_reaches_healthfundingagreementwithbritishcolumbia.html.

¹³ "Ontario, Quebec and Alberta Sign Health-Care Deals with Federal Government." CBC News. Accessed November 29, 2017. <http://www.cbc.ca/news/politics/health-care-deal-ontario-quebec-1.4019212>.

¹⁴ Standing Senate Committee on Social Affairs, Science and Technology. "The Health of Canadians - The Federal Role: Final Report on the State of the Health Care System in Canada." Government of Canada, October 2002. 142.

¹⁵ Standing Senate Committee on Social Affairs, Science and Technology, "Pay Now or Pay Later," 14.

¹⁶ Government of Canada, "Budget 2017: Building a Strong Middle Class," 133-4.

disabilities, which will do little to reduce the current waitlist of 14,000 people.^{17 18} Housing waitlists are not only detrimental to those with ASD and their families, but create a substantial cost to government as well. This cost stems from family members exiting the job market to act as caregivers, and from persons with ASD being placed in inappropriate housing, such as a hospital or correctional facility.^{19 20} Therefore, the funding of additional housing units for individuals with ASD should be a priority.

Given the shortage of supportive housing, the government should also support the housing needs of individuals with ASD living with family. One way this could be accomplished is through an expansion of the Home Accessibility Tax Credit, which is currently geared toward people with physical disabilities and seniors.²¹ Expanding this credit to explicitly cover home modifications that address the needs of individuals with ASD, such as sensory-related modifications or home-repairs related to repetitive behaviour, could improve the safety, wellbeing, and financial situations of individuals with ASD and their families.²²

Recommendation 4: Partner with Indigenous peoples to ensure children with ASD receive services in a culturally appropriate manner

An essential part of a national ASD strategy is the participation of Indigenous peoples in its development. Many of the early intervention practices used for children with ASD are grounded in a Western model of health, which focuses deficits, diagnostic labels, and an individualistic view of health.²³ This not only stands in contrast to the holistic and strength based approach to health held by many Indigenous communities, but may also perpetuate the colonial practice labelling and stigmatizing Indigenous peoples. The cultural and linguistic diversity of Indigenous Canadians also means that services available to Indigenous peoples may not be culturally appropriate. For example, children with ASD often work with speech-language pathologists to develop their communication skills. This presents a challenge, as many language assessment tools are developed from a Western perspective and may systematically penalize the use of nonstandard English dialects spoken in some Indigenous communities.²⁴ The participation of

¹⁷ "Liberals Detail \$40B for 10-Year National Housing Strategy, Introduce Canada Housing Benefit - Politics - CBC News." Accessed November 29, 2017. <http://www.cbc.ca/news/politics/housing-national-benefit-1.4413615>.

¹⁸ "Parents, MPPs Rally for Funding for Developmentally Disabled Adults - Windsor - CBC News." May 10, 2017. <http://www.cbc.ca/news/canada/windsor/parents-mpps-rally-for-funding-for-developmentally-disabled-adults-1.4108787>.

¹⁹ Ibid.

²⁰ "Ontario Family Takes Drastic Measures to Find Care Home for Son with Autism - Toronto | Globalnews.ca," November 9, 2015. <https://globalnews.ca/news/2329329/ontario-family-takes-drastic-measures-to-find-care-home-for-son-with-autism/>.

²¹ Canada Revenue Agency. "Home Accessibility Tax Credit (HATC)." Financial material. May 25, 2015. <https://www.canada.ca/en/revenue-agency/programs/about-canada-revenue-agency-cra/federal-government-budgets/budget-2015-strong-leadership/home-accessibility-tax-credit-hatc.html?wbdisable=true>.

²² Wasan Nagib, and Allison Williams. "Toward an Autism-Friendly Home Environment." *Housing Studies* 32, no. 2 (February 17, 2017), 149, 163.

²³ Alison Gerlach, *Steps in the Right Direction: Connecting & Collaborating in Early Intervention Therapy with Aboriginal Families & Communities in British Columbia*, 2007, http://www.acc-society.bc.ca/files_2/documents/StepsintheRightDirection2007.pdf, 16-17.

²⁴ Sharla Peltier, "Facilitating Language and Literacy Learning for Students with Aboriginal English Dialects." *Canadian Journal of Native Education* 32 (2010): 114-42.

Indigenous peoples in developing Canada's national ASD strategy will help to ensure policies respect Indigenous perspectives on health, and encourage the development and delivery of culturally appropriate services.

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