

Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

By: The Canadian Autism Spectrum Disorder Alliance (CASDA)

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I. Recommendations:

- 1. Present a project plan for a National Autism Strategy (NAS);
 - A. Appoint a senior bureaucrat to lead a NAS, with responsibility for spearheading collaborations between federal, provincial and territorial governments in policy related to autism;
 - B. Implement a cross-government senior civil servant working group in relation to informing a NAS;
 - C. Commit to reforming the Disability Tax Credit.
- 2. Implement targeted consultations on specific issues related to a National Autism Strategy that have not been previously addressed with appropriate amounts of funding and a transparent selection process. Include specific budget lines to enable Autistic Canadians to actively participate in the consultations.
- 3. Appoint an Autism Advisory Panel to support and collaborate with government in relation to the development of a National Autism Strategy with appropriate amounts of funding and a transparent selection process. This needs to include Autistic Canadians and ought to incorporate an intersectional lens in relation to gender, BIPOC, people from rural and remote communities, immigrants and refugees, as well as representation from the LGBTQ+ community.
- 4. Collaborate with Indigenous partners in relation to the creation of a separate, distinctions-based approach to a National Autism Strategy;
 - Appoint a lead government representative to activate engagement with First Nations leadership to facilitate the collaboration needed to create a distinct National/Indigenous Autism Strategy.
- 5. Develop a body of evidence regarding the performance of measures in relation to the development of a National Autism Strategy.
- 6. Host federal/provincial/territorial meetings in relation to how the government can assist provinces and territories in working collaboratively to support Autistic Canadians.
- 7. Incorporate strategies to engage institutions and employers to promote best practices for inclusion of Autistic Canadians, building upon current investments for the economic growth in the coming year, and ensuring that the benefits of all economic investments are accessible to Autistic Canadians.

II. Introduction

CASDA is pleased to present its 2021 federal budget recommendations to the House of Commons Standing Committee on Finance, with measures to advance the development and implementation of a National Autism Strategy (NAS), all of which are in line with the committee's theme for this year being to "restart the Canadian economy, as it recovers from the COVID-19 pandemic".

On December 9th, 2019, the federal government announced its commitment to developing and implementing a NAS, and has since tasked the Minister of Health, Minister Patty Hajdu and the Minister of Employment, Workforce Development and Disability Inclusion, Minister Carla Qualtrough with leading this vital work.

CASDA is an alliance of autism organizations, service organizations, researchers, professionals and Autistic Canadians. We coordinate national conversations about autism. CASDA was formed in July 2007 shortly after the Senate Committee Report "Pay Now or Pay Later: Autism Families in Crisis". During this time the federal government sent a clear message to the Autism community: Work together with a unified voice. The Autism community responded by forming CASDA. Together, we represent over 500,000 autistic Canadians, their caregivers, researchers, and service providers working to enhance their experience and inclusion as Canadians.

CASDA is asking the government to develop a NAS that is ambitious and far-reaching in its scope and impact. The NAS needs to reach across government and will require careful coordination and buy-in between departments. Together we can develop a more comprehensive suite of actions to improve the quality of life of people on the Autism Spectrum in Canada, and their families.

III. COVID-19 and Autistic Canadians

The COVID-19 pandemic has ravaged the Canadian population, from its attack on our health and well-being to its attack on our economy. As Canada's economy falters, Autistic Canadians are positioned to be one of the most disadvantaged. Autistic Canadians are faced with economic vulnerability, with many young autistics entering into entry level positions, most of which have been drastically influenced by the pandemic, making an already extremely difficult transition from school to the workplace even harder. Additionally, Autistic Canadians often find themselves in short contract positions, which have been severely impacted as a result of COVID-19. With four of five adults with ASD out of the labour force entirely prior to the

pandemic¹, the reality that these Canadians face is daunting. Time is of the essence to develop and implement a NAS, as without appropriate supports that fit their needs, individuals on the Autism Spectrum and their families will see drastically worse health, education, employment, and quality of life outcomes², a reality that has only been worsened with the onslaught of the COVID-19 pandemic.

Autistic adults represent a large community of individuals with the knowledge and skills that would make them valuable members of the economy when given the opportunity. With the number of Autistic Canadians estimated to be approximately 500,000, these Canadians represent a key community that must be engaged in the process of Canada's economic recovery following the impacts of the COVID-19 pandemic. The development and implementation of a NAS will provide Autistic Canadians the support they need in order to contribute their fair share to economic recovery efforts. By championing Autistic Canadians, they will be champions of Canada's recovery from the aftermath of the COVID-19 pandemic.

IV. Explanation of Recommendations:

CASDA recommends that a NAS be developed to include a full suite of concrete actions that will directly impact the lives of autistic people and their families. Through presenting a project plan for a NAS, the government will begin the process of ensuring that Autistic Canadians have full and equal access to the resources they require to achieve their full potential as members of Canadian society. One of the key first steps to achieving a project plan is committing to "early wins" as outlined in CASDA's *Roadmap to a National Autism Strategy*. "Early wins" were designed to help the government show clear leadership and commitment right away to a NAS while simultaneously helping Autistic Canadians and their families immediately. Building on the progress from the 2019 budget on the Disability Tax Credit, by committing to its reformation, the government will announce its commitment to tax fairness. Simultaneously, the government should also reach across other government activities and strategies to ensure that Autistic Canadians and their families are taken into consideration even when they are not the primary population being served by a program or policy. To achieve this, CASDA calls for a **cross**-

¹ Jennifer Zwicker, Arezou Zaresani, and J. C. Herb Emery, "Describing Heterogeneity of Unmet Needs among Adults with a Developmental Disability: An Examination of the 2012 Canadian Survey on Disability," Research in Developmental Disabilities 65 (June 2017): 1–11, https://doi.org/10.1016/j.ridd.2017.04.003.; Alisha C. Salerno and Regina A. Schuller, "A Mixed-Methods Study of Police Experiences of Adults with Autism Spectrum Disorder in Canada," International Journal of Law and Psychiatry 64 (May 1, 2019): 18–25, https://doi.org/10.1016/j.ijlp.2019.01.002.

² Canadian Autism Spectrum Disorder Alliance (CASDA). *Blueprint for a National Autism Spectrum Disorder Strategy*. PDF. March 2019.

government senior civil servant table meeting at regular intervals to coordinate the development and implementation of the strategy.

Necessary to the development of a NAS is that it is informed by Autistic Canadians and key stakeholders through meaningful consultations. Without hearing directly from Autistic Canadians and their communities, a NAS runs the risk of potentially increasing barriers that autistic individuals must overcome as a result of residing in Canada. Consultation is vitally important, but CASDA urges government to not proceed as if it were starting from zero and urges the government to be targeted and efficient in its approach. Many of the foundational questions have been posed and answered in previous processes, including the <u>Canadian Autism Partnership Project</u> and the 2014 <u>CASDA National Needs Assessment</u>. Autistic Canadians are eager to see government action. CASDA, therefore, recommends that government engage in meaningful consultations that respectfully build on what has already been researched.

In addition to this, to ensure Autistic Canadians and their needs are considered in all government work, and not simply in relation to the NAS, CASDA asks the government to **develop an Autism-informed lens** to be applied to policy proposals. The impact of government on Autistic Canadians goes far beyond programs and policies that specifically target them. Any government program or policy can have a different, and often unintended, impact on an Autistic Canadian relative to another Canadian. Autism is a truly intersectional issue that requires a subtle, cross-government approach.

To prevent the potential further marginalization of Autistic Canadians, CASDA asks government to develop and apply an Autism-informed lens to its policy development and economic strategies. This means that Canadians on the Autism Spectrum and their distinct needs are incorporated in a systematic manner into government policy development, ensuring strategies, policies, and investments are inclusive. To support this work, including implementing the Autism-informed lens, and to provide a resource to government's policy and program development within a NAS and outside it, CASDA also asks the government to develop an Autism Advisory Panel made up of individuals with lived experiences, family members and experts in the field with an emphasis on including Autistic voices. CASDA recommends that the role of panel members should be advisory in nature and not advocacy toward a particular outcome. Members ought to include autistic people and incorporate an intersectional lens with women, Indigenous peoples, people from rural and remote communities, racialized immigrants and newcomers, and from the LGBTQ+ community.

To ensure that the specific needs of Indigenous communities in Canada are met, a NAS ought to ensure that all Autism programs, and not just those designed specifically for Indigenous people, are culturally safe and appropriate for Indigenous people, and for vulnerable populations.

Furthermore, it is essential that the government appoint a lead government representative to move Indigenous engagement beyond collaboration and facilitate the process to allow Indigenous communities to develop Indigenous-specific strategies. This will allow the most appropriate responses to Indigenous people with autism. Thus, CASDA recommends that government catalyzes the development of separate, distinctions-based approaches for Indigenous Autistic Canadians.

A NAS cannot succeed if it does not measure its progress. In order to do this, CASDA asks the government to collaborate with CASDA, researchers, and the Autism community to set a series of objectives and success measures, focusing on clear outcomes, to track the progress of a NAS. This will not only maintain momentum and accountability; it will also allow government to take an evidence-informed approach to re-assessing and revitalizing the NAS over time. The NAS should be sustainable, efficient and provide real outcomes for Autistic Canadians and their families. To do this, we ask the government to develop a body of evidence on what is working, to aim for continuous improvement, and to have annual, public-facing report backs on progress.

Across Canada, autistic individuals navigate different levels of support depending on in which province or territory they reside. This has resulted in many Autistic Canadians moving crosscountry in order to gain necessary access to more inclusive governmental assistance. While the community recognizes the distinction between federal and provincial or territorial jurisdiction in this space, Autistic Canadians and their families expect their leaders to work together to have coordinated and collaborative responses so that all Canadians can access the support they need regardless of where in the country they live. By sharing best practices and collaboratively addressing similar shared challenges, Autistic Canadians would not be forced to move in order to access necessary supports. To achieve this, CASDA urges the government to open a dialogue about Autism between all levels of government - federal, provincial and territorial through Ministerial FPT meetings.

Finally, as government moves forward in recovering the economy in wake of the devastation that COVID-19 has left and continues to leave, Autistic Canadian are positioned as an employable community that, with proper and adequate support, can be instrumental to Canada's recovery. Thus, CASDA proposes, that the government build strategies to engage institutions and employers to promote best practices for inclusion of Autistic Canadians.