



**In keeping with the commitments of the Canadian Autism Spectrum Disorder Alliance (CASDA) to advocate for the rights of Canadians with Autism Spectrum Disorder (ASD) and to work with the Federal Government to address their needs, CASDA developed and regularly updates its position on the pressing issues facing individuals with ASD and their families, as well as suggestions for targeted action by the Federal Government.**

**ISSUE:** There is an urgent need for a comprehensive ASD strategy that leverages collaborative impact to address the needs of Canadians with ASD. CASDA calls this plan a National ASD Strategy. All stakeholders must work together to improve the outcomes for Canadians with ASD and their families. Federal Government support is essential to the successful development of a comprehensive and effective National ASD Strategy.

**CURRENT SITUATION:** ASD is the most commonly diagnosed neurological disorder in Canada. It is a lifelong condition that manifests itself in a wide-range of symptoms, including difficulty communicating, social impairments, and restricted and repetitive behaviours. Individuals with ASD face challenges that most Canadians would find untenable. Once considered a rare disorder, statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify approximately 1 in 68 children as being on the autism spectrum. Rates of diagnosis continue to increase. The Public Health Agency of Canada will be releasing autism prevalence data in 2017.

*Learning that your child has ASD is overwhelming. Parents often get lost in a fragmented system trying to navigate and understand what they need to do to support their loved one through childhood and during their adult years. Depending on where you live in Canada, wait times to access services and supports are often measured in years.*

There is evidence that individuals with ASD experience reduced quality of life across many of the social determinates of health including: income and social status, social support networks, education, employment/working conditions, social environments, healthy child development, personal health practices and coping skills. There is consensus that when appropriate and coordinated supports are accessible across the lifespan, quality of life improves for individuals with ASD and their families.

In the past few years, CASDA has surveyed almost 10,000 Canadians including family members, adults with ASD, federal and provincial government representatives and professionals.

In 2014, CASDA, with the support of the Public Health Agency of Canada, conducted a National Needs Assessment Survey. It remains the largest survey of stakeholders across Canada to date, with over 5600 respondents. The subsequent report [Autism in Canada: A National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals, 2014](#) identified several priorities.

Following *Autism in Canada*, CASDA engaged in the Canadian Autism Partnership Project (CAPP). The input received from 4,963 Canadians representing all ten provinces and three territories, echoed the Autism in Canada priorities and strongly supported a collective impact model as described in [Better Together: The Case for a Canadian Autism Partnership](#).

CASDA recognizes that there are challenges to enabling full participation in our Canadian society for individuals with ASD so that outcomes across the lifespan improve. But solutions must be found. Coordination of efforts and information would be guided by a National ASD Framework. A commitment to working together, as well as, measuring and sharing impactful results is required.

## FEDERAL ADVOCACY AND ACTION

The Minister of Sport and Persons with Disabilities, has been tasked with leading an engagement process with provinces, territories, municipalities, and stakeholders that will lead to the passage of a Canadians with Disabilities Act. The forthcoming legislation, while promising, is not by itself enough to improve the outcomes for individuals with disabilities, including ASD. Collective action in a number of areas is required.

CASDA has identified several concrete actions, in nine key areas, that the Federal Government can take action on now to improve the outcomes for individuals with ASD and their families.

**BEST PRACTICES IN SERVICES AND SUPPORTS:** Across Canada, approaches and access to supports for individuals with ASD are inconsistent and many gaps exist. The approach to diagnosis, interventions, transitions, education, housing, employment, and health care are different and access is varied. The Federal Health Department has historically set the pace in identifying and monitoring best practices and disseminating this information across the country. A similar mechanism for identifying best practices across all of the social determinates of health would help ensure consistency, coordination and effective use of resources. It is critical that all stakeholders work together to facilitate broad and accurate communication of best practices for ASD.

**EMPLOYMENT:** The Federal Government currently has a number of Ministries supporting employment related programs and services that are meaningful to individuals with ASD and their families. CASDA appreciates the impact of every initiative that supports people with disabilities and encourages the Federal Government to continue supporting these programs. The Minister of Employment, Workforce Development and Labour has an opportunity to ensure that the Labour Market Agreements with provinces are meaningfully increasing the labour force participation rate for individuals with ASD.

**FINANCE:** The Minister of Finance has an opportunity to ensure that disability benefits and the disability savings plan are configured to optimally support individuals with disabilities throughout their lives. The Income Tax Act and the application of its regulations must be reviewed. Expenditures for treatments and services recommended by licensed professionals, including Pediatricians, Psychologists, Occupational Therapists, Speech Pathologists etc., should be recognized as qualified medical deductions on Federal tax returns. The Disability Tax Credit Application should be ASD friendly, and be revised to include a section that qualifies the ASD applicant more readily.

**HEALTH:** The Federal Government has signed health agreements with every province and territory. The agreements include targeted dollars for home care and mental health. The agreements require the province to present a plan to the federal government and the public on how they will spend their targeted funds. CASDA reports from both CAPP and *Autism in Canada*, identified the development of accessible mental health services for youth and adults with ASD as priorities. The targeted mental health dollars present an opportunity to address the significant barriers to accessing mental health services that prove challenging for thousands of individuals with ASD and their families. CASDA would also encourage Health Canada to consider ASD from the perspective of a chronic, life-long condition, and find approaches that optimally support the physical and mental health of individuals with ASD. Encouraging provinces to develop measures that address the substantial barriers related to access to early diagnosis and intervention, navigating support services, reducing waitlists, addressing financial constraints and facilitating the transition from pediatric to adult care will significantly improve the quality of life for individuals impacted by ASD.

**OUTREACH TO LINGUISTICALLY AND CULTURALLY DIVERSE COMMUNITIES SUCH AS FIRST NATIONS:** Canadians need better ASD-specific supports that are consistent with their culture and can be provided within their communities. CASDA's report, *Autism in Canada: A National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals, 2014* clearly demonstrated the need for a unique strategy to reach out to these groups of Canadians who may be further marginalized by an ASD diagnosis. Recognizing the Federal Government's deliberate attention to diversity, it is an opportune time to focus on outreach to linguistically and

culturally diverse communities. A National ASD Strategy must be respectful of Canada's multi-cultural makeup and must engage directly with First Nation peoples to find ways to address their unique barriers to effective services and supports.

**HOUSING:** The Federal Government has committed \$30 Billion to a National Housing Strategy. Ideally, the National Housing Strategy will provide a clear path to accessing dollars to support a variety of housing solutions for individuals with ASD. The strategy must adopt a flexible approach to incorporating the broad range of support needed to address varying levels of need among Canadians with ASD.

**RESEARCH:** A significant increase in ASD-specific research funding that addresses ASD as a whole body, spectrum disorder including genetic targets and environmental triggers is urgently needed. Within this context, there must continue to be research and evaluation to support the pursuit of best practices in intervention, while investigating and better understanding risk factors relating to this disorder. Research into the causes and better treatment options must be a priority. As part of a National ASD Framework, Canada must continue to be a leader and support advancements in research that lead to improved outcomes for individuals living with ASD.

**SURVEILLANCE:** In January 2011, the Public Health Agency of Canada (PHAC) established an autism unit mandated to develop a National ASD Surveillance System (NASS). The unit is collecting comparable, comprehensive regional and national-level data needed to characterize and accurately report on estimates of ASD prevalence among children and youth in Canada. Such data is critical to filling knowledge gaps, informing public health responses and advancing strong evidence-based solutions to help improve the lives of Canadians affected by ASD. A National ASD Strategy based on comprehensive Canadian surveillance data will benefit Canadians.

**TRAINING PROFESSIONALS:** The recruitment and training of multidisciplinary professionals across the ASD field is critical to our knowledge surrounding ASD and how individuals and families are supported. Primary healthcare providers, educators, researchers, and health sciences service providers (i.e.) speech language pathologists and occupational therapists are often the first point of contact families make when they have an inquiry or concern regarding their child's development. These professionals also make up the team of support surrounding individuals with ASD across their lifespan. Due to the multiple facets of ASD, the Federal Government could support the ASD community in championing a comprehensive training program focusing on increasing the ASD related knowledge of professionals ensures Canada's capacity to support the large population impacted across our country.

**SUMMARY:** With ASD prevalence statistics on the rise, researchers, government systems, and community based organizations need to work together and adapt quickly to support the needs of this growing global health and disability-related crisis. The 2007 Senate Committee report, *Pay Now or Pay Later*, presented a set of recommendations that ten years later are still relevant. It is time for coordinated action.

The Federal Government is in a unique position to be a facilitator, by supporting the engagement of provinces and territories in much needed dialogue. The challenge before us is to find effective ways to leverage the strengths of our federal and provincial systems, as well as previous investments to better serve people with ASD. Working together we must advance the ASD agenda in Canada to provide consistency in information, treatment and services.

CASDA is well positioned to work with all stakeholders to advance a National ASD Framework. CASDA represents a unified voice within the Canadian ASD community and is prepared to build on its successful track record of working in partnership with the Federal Government and its ministries to support the development of a comprehensive Strategy that will address the needs of Canadians with ASD.

September 2017