

CASDA

**THE CANADIAN ASD ALLIANCE
WORKING IN PARTNERSHIP WITH
THE FEDERAL GOVERNMENT**

*Position Paper Supporting a National Autism
Spectrum Disorder (ASD) Strategy*

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

Individuals with ASD face challenges that most Canadians would find untenable. Once considered a rare disorder, ASD is now believed to be diagnosed in 1 in 68 Canadian children. (This statistic is based on estimates from the United States, Centre for Disease Control and Prevention's (CDC). We anticipate the Public Health Agency of Canada will be releasing autism prevalence data as early as 2016). Unemployment among able-bodied individuals with ASD is well above 50%. Mental health issues are experienced by almost 70% of Canadians with ASD.

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 2016.

Learning that your child has ASD is overwhelming. Parents 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, coordinated supports are accessible and incorporated across the lifespan, quality of life improves for individuals with ASD and their families.

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 (including family members, adults with ASD, and professionals) reporting on their experiences and opinions. The report *Autism in Canada: A National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals, 2014* identified several priorities:

- Early identification and timely access to diagnosis, intensive behavioural intervention, parent support, and other forms of evidence-based early intervention;
- The development of accessible mental health services for youth and adults with ASD;
- Outreach to independent adults with ASD, a large group of Canadians, many of whom are living on the periphery of their communities and often outside of the network of services;
- Comprehensive planning for adulthood, including transition support and housing;
- Outreach to address the unique issues of Canada's northern communities;
- Targeted outreach to linguistically and culturally diverse communities, such as our indigenous peoples.

CURRENT SITUATION *Continued*

In 2015, building on the priorities identified in the Autism In Canada Report, CASDA proposed a Canadian Autism Partnership model to the federal government, which received initial support and project funding in the 2015 Economic Action Plan budget announcement. CASDA recognizes that meaningfully addressing the complex, multi-jurisdictional and cross-sectorial issues that present obstacles to full participation in our Canadian society for individuals with ASD will require a commitment to collective impact. Collective impact involves maximizing the impact of partnerships by bringing together people, experience and resources to address complex social issues. The Canadian Autism Partnership is designed to support this collective impact approach and is a next step towards a National ASD Strategy.

In 2016, the Minister of Sport and Persons with Disabilities, The Honourable Carla Qualtrough, 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. CASDA would ask the Federal Government to ensure that a mechanism is built into the process so that input from the ASD community is incorporated into this significant piece of legislation.

CASDA has identified several concrete actions in eight 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 & 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, The Honourable Mary Ann Mihychuk, 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, The Honourable William Morneau, 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 recently tasked the Minister of Health, The Honourable Jane Philpott, with engaging provinces and territories in the development of a new multi-year Health Accord. CASDA appreciates the Federal Government's leadership and focus on this timely and relevant conversation. The new Health Accord presents an opportunity to address the significant barriers to health services that prove challenging for hundreds of thousands of individuals with ASD and their families. Based on the complexity of the disorder, supporting a clear interdisciplinary approach in the development of a new Health Accord is necessary. CASDA would ask the authors of the Health Accord 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. Incorporating 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 & 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 such as First Nations. A National ASD Strategy must be respectful of Canada's multi-cultural makeup and First Nation peoples by finding ways to address their unique barriers to effective services and supports.

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. There is a great opportunity to study the area of environmental triggers working in the presence of a genetic predisposition. Research into the causes and better treatment options must be a priority. As part of a National ASD Strategy, 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 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. CASDA's report, *Autism in Canada: A National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals, 2014*, which builds on the important work found in the 2007 Senate Committee report, *Pay Now or Pay Later*, presents a set of recommendations that can be used to start the work that is needed.

The Federal Government is in a unique position to be a facilitator, engaging the 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 Strategy. CASDA represents a unified voice within the Canadian ASD community and is prepared to work in partnership with the Federal Government and its ministries to outline this comprehensive plan that will address the needs of Canadians with ASD. The recent funding to of the Canadian Autism Partnership Project will provide an invaluable opportunity to consult with stakeholders across Canada and further refine the components of a comprehensive National ASD Strategy.