

Developing a pan-Canadian transformative partnership to build the capacity to address Autism Spectrum Disorders in Canada

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The state of autism in Canada requires that the Federal Government exercise a leadership role. The country needs national comprehensive care across the current provincial health, education and social services systems to ensure that autism treatment and support are consistent across all environments and jurisdictions.

Autism Society Canada offers a solution for the Federal Government by creating an innovative transformative partnership to address this Canadian challenge.

Autism Society Canada (ASC) is a grassroots organization founded in 1976 by a group of parents committed to advocacy, public education, information and referral, and support for its regional societies. Each provincial and territorial autism societies and their member groups provide direct support to individuals living with Autism Spectrum Disorders (ASDs) and their families. Today, as a federation of Autism Societies, represented by each of the ten provinces and two territories, Autism Society Canada embodies the largest collective voice in the Canadian autism community.

An Autism Spectrum Disorder is a neurological disorder that causes developmental disability. The term “spectrum” refers to a continuum of severity or developmental impairment. Individuals living with Autism Spectrum Disorders develop differently from others in the areas of motor, language, and cognitive and social skills. This is why Autism Society Canada works to offer uncensored resources and information on a variety of options covering a wide spectrum, allowing for individual differences in treatment or service options.

In Canada we estimate Autism Spectrum Disorders affects hundreds of thousands of individuals, their families and nearby community - this is why we need to give this immediate National attention.

We understand that the responsibility for the delivery of direct health care services, in hospitals and in the community, and the legislation governing standards of care, rests with the provincial and territory. In addition to these required services, provincial and territorial government may also offer additional benefits at their own discretion and on their own terms and conditions. But it must be emphasized that appropriate quality of life for individuals living with autism and their families would reduce the cost of services to the provincial health and social service system. We estimate these cost to be more than one billion dollars annually. (ANNEX II)

Additionally, there are inequalities in services and supports across all age groups and across the country. Under the Canadian Health Act, the provincial and territorial governments are required to provide medically necessary hospitals and physician services to all eligible residents on a prepaid basis. However, access to best practice treatment for Autism Spectrum Disorders varies according to province or territory.

The following is a multi-year solution to enable the Federal Government to address this priority issue for all Canadians. Autism Society Canada proposes a cost effective solution that would demonstrate:

- Federal leadership.
- National innovation.
- With a multi-sectorial approach.

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A pan-Canadian initiative needs to be put in place to address Autism Spectrum Disorders in Canada. This partnership would be coordinated by Autism Society Canada and funded by the Federal Government via the department of its choice.

ISSUES:

There is an urgent need to take a leadership role in addressing Autism Spectrum Disorders in Canada. No other medical condition in Canada is being treated in such an out of date manner that affect families across the country. The medical and scientific communities have endorsed Applied Behavior Analysis (ABA) or Intensive Behavioral Intervention (IBI) and multiple studies over more than 20 years demonstrate its usefulness. Of course it is not a cure and does not work for everyone, but it helps many of the individuals living with an Autism Spectrum Disorder. The autism community has so far still be ineffectual in achieving any major breakthrough in federal policies and programs that would ensure equal access across the country to ABA/IBI in a timely fashion.

Federal, provincial and territorial governments have recognized the critical role of social attitudes in recent work on a national mental health strategy and a national cancer strategy. Each province and territory can also participate in developing, and being responsible for reporting against, common standards.

SOLUTION:

A consultative body (name to be determined – maybe a *Council*) needs to be created to better inform Health Ministers whilst allowing for a consultative process with the autism community. This structure would include individuals appointed by the Federal, provincial and territorial governments, along side with key stakeholders. This Council will provide advice to the federal, provincial and territorial (F/P/T) Deputy Ministers of Health in support of their efforts to coordinate related activities. Provincial and territorial government would fund those elements of the strategy, which fall within provincial and territorial health systems.

An Autism Council provides a mechanism to channel federal attention, funds, and manpower on specific challenges related to Autism Spectrum Disorders in Canada.

Autism Society Canada's goal is to establish collaboration with Canadian governments, to address prevention, life maximization and cost minimization of this life-long condition through universally available autism expertise. This can help provide a better understanding of autism screening, diagnosis and assessment services, scientifically validated effective autism treatments and condition improvement actions as well as proactive adequate family supports and assistance.

To date, Autism Society Canada has continued to work with all stakeholders on a number of key issues:

- Autism Society Canada is the only Canadian Autism Organization present in 10 provinces and 2 territories. Hence ASC is capable of providing expertise for the development of standards and recommendations for future consideration.
- Autism Society Canada is the only Canadian organization actively encouraging the inclusion of individuals living with an Autism Spectrum Disorder. ASC's *Advisory Committee of Adults living with an ASD*, ensures these individuals are involved not only in their own provincial or territorial autism societies but also at the national level.

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Canadians need a national comprehensive care across the current provincial health, education and social services systems to ensure that autism treatment and support are consistent across all environments and jurisdictions.

ISSUES:

Having access to best practice treatment for Autism Spectrum Disorders varies according to province or territory. In addition, there are inequalities in services and supports across all age groups and across the country. From coast to coast, dealing with Autism Spectrum Disorders is inconsistent. Whether it is under the umbrella of health and/or community services, every province or territory reinvents a solution to address the growing needs of its ASD community. Depending where you live in this country, the accessibility of a multidisciplinary approach varies, based on availability and cost.

The Federal Government must work with the provinces to break down the silos and avoid wasteful duplication that exist across the country. It is understood that funds transferred from Ottawa to the provinces/territories for Health issues are not conditional; we believe that Health Canada can provide statements that underscore and promote resources related to Autism Spectrum Disorders.

SOLUTION:

By establishing a coordinating capacity, Autism Society Canada can ensure we have a co-ordinated, comprehensive and integrated strategy. Autism Society Canada has had several opportunities to network and partner with national organizations. All of our key activities have enabled us to bring the needs of the Autism Spectrum Disorders community into public awareness on a variety of fronts.

This partnership can enable the Federal Government a leadership role in facilitating:

- National standards and national application of responsibility for care and treatment of people with autism. It is not an education or social services. Autism Spectrum Disorders are medical conditions affecting all of Canada that require national standards with a plan of consistent, effective and accurate medical screening, diagnosis, treatment and support.
- The solution involves the Federal Government, provincial and territorial governments as well as community stakeholders.

Additionally, Autism Society Canada continues to strive to help shape and inform Canadian policy makers in regards to the life of individuals living with ASDs, their families and caretakers. Autism Society Canada has had several opportunities to network and partner with national organizations.

- We partner with Public Health Agency of Canada in 2008 for a pilot surveillance assessment.
- Autism Society Canada is also a founding member of the Canadian Autism Spectrum Disorder Alliance (CASDA), created in 2009. This Alliance is currently very active with Health Canada in the development and implementation of its surveillance system.

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Act in a collaborative, coordinated approach to develop a pan-Canadian partnership that would enable the Government of Canada to assess, develop and draft its Canadian Autism Strategy, reaching across federal and provincial lines to foster partnership and engage collaborative solutions.

ISSUES:

The United States and the United Kingdom have legislation to support national strategies for autism. New Zealand's Ministry of Health has been able to adapt its "Autism Spectrum Disorder Guideline" to meet the individual and unique needs of its different populations, i.e., Maori.

Currently there exists no national framework from which to establish minimum standards. Provinces re-invent, readapt or rebuild makeshift solutions and stop gap services in order to address the needs of individuals living with an ASD. Federal structures have successfully been implemented to address controversial and multi-dimensional health issues such as Mental Health, Cancer or Foetal Alcohol Syndrome.

We need to develop a creative solution for specific issues that can be used as templates for addressing Autism on a national platform. There are economies of scale in building on existing capacities and developing a broad multi-sectorial approach to ASD initiatives.

SOLUTION:

The development of a partnership with Autism Society Canada would enable the Federal Government to establish a broad, multi-sectorial approach through a Canadian National Autism Strategy, governments could effectively establish minimum standards such as:

- Establish a national surveillance mechanism to effectively track individuals living with an ASD.
- Define minimum standards of service and treatments and professionals across the country to ensure equal access to services across Canada.
- Promote autism awareness through a national awareness campaign targeted at individuals, health care professionals, and first responders (fire, ambulance etc.).

ASC can help identify existing solutions to help shape a national strategy. There already exist successful collaboration in some provinces. We can use a model, i.e. Nova Scotia's Action Plan, Newfoundland's Centre... All of these help share best practices to accelerate the process of informing solutions.

Autism Society Canada is also involved in pilot projects such as a National Registry (different from a surveillance system). To help gather existing disparate grass roots initiatives whilst at the same time providing information to help manage the environment when responding in emergency situations.

As a partner, ASC can facilitate the pilot for the creation of a "Model Centre". ASC will use the expertise it has developed over the last 35 years, for instance with remote communities, isolated or diverse cultural groups. This will facilitate the development of a first "Flagship model" shaping solutions for all future audiences.

This partnership would provide the capacity to offer advice on a national autism strategy across the country. This is essential to the federal, provincial and territorial (F/P/T) Deputy Ministers of Health in support of their efforts to coordinate related activities.

Conclusion:

The Federal Government is already showing leadership with its involvement in other disorders. A multi-departmental approach with a high degree of collaboration between provinces, territories, individuals, and autism stakeholders can be developed to address this multi-disciplinary challenge. This partnership can enable the development and implementation of a plan for a national strategy along side the autism community.

Federal, provincial and territorial governments have recognized the critical role of social attitudes in recent work on a national mental health strategy and a national cancer strategy. Autism *Council* will provide an evaluation plan for a national strategy. Each provinces and territories can then participate in developing, and reporting against, common standards. Provincial and territorial government would fund those elements of the strategy, which fall within provincial and territorial health systems.

It is time now to address Autism Spectrum Disorder in Canada. Building on Autism Society Canada's 35 years of experience in the autism community Autism Society Canada can contribute to make this a transformative partnership resulting in the development of a Canadian Autism Strategy

Cost for 4 years:

Already involved in developing a surveillance system, Health Canada is recognizing autism as a priority health issue. We now need to take a leadership role in addressing autism conditions in Canada. There is a *Financial Impact Summary* is attached in Annex II for consideration. Autism Society Canada is the only Canadian organization that can successfully implement such a partnership. The Federal Government needs to provide:

\$2,400,000 (\$600,000 per year): Full-time equivalence for Autism Society Canada's team is required to support this partnership and develop sustainable coordinating capacity across the country with its 12 provincial and territorial societies. With the possibility of creating a society in Iqaluit.

This cost represents a saving for the Federal Government. The alternative would be the development and creation of a permanent department/division within Health Canada or in a Ministry of the Federal Government's choice.

\$1,000,000: To develop and coordinate the development of a *Model Centre* in a remote region. Identifying Iqaluit is both relevant and timely to develop such a pilot. This involves research for models, best practice development, acute regional needs assessment and the coordination to develop the *Model Centre*.

This is a one-time cost to be assessed after 3 years. The outcome could be the creation of a model to be used and implement across the country. This pilot would offer all provinces and territories that chose to use this model, or components of it, important economies of scales.

\$0: Holding at least one (F/P/T) Health Minister conference with an agenda item on Autism Spectrum Disorders. This is already an occurring cost for the Federal Government.

ANNEX I

Autism Society Canada www.autismsocietycanada.ca

For 35 years now, Autism Society Canada's mission as remained:

- To promote federal policies, programs, and legislation that respond to the needs of the Autism community.
- To promote the rights of families and individuals living with ASDs universal access to all treatments and services that work in their best interest.
- To promote the rights of families and individuals to interests of the individual with an ASD.
- To increase awareness and understanding of Autism Spectrum Disorders and acceptance and participation of individuals with ASDs.
- And to continue to promote intervention research that will provide individuals with ASDs and their families with practical support.

Our vision is that all individuals living with Autism Spectrum Disorders achieve their individual potential and that they and their families have universal access to the resources they require.

Autism Society Canada is proud to be one of the only bilingual national website portals providing resources on lifespan issues to the ASD community. Along with supporting a growing number of requests, we are often the first point of contact for parents and other family members who are concerned about love ones or who have received a recent diagnosis. Many individuals living with an ASD themselves turn to us for resources and we are frequently contacted by researchers and professionals seeking resources on ASD-related issues. Autism Society Canada makes it a priority to share these valuable resources on lifespan issues to reduce the impact of ASDs for individuals and their families.

Most of the calls we receive at ASC are from families who are at the end of their ropes, and are looking in vain for services specific to the needs of their children with autism.

Today, as a federation of Autism Societies, represented by each of the ten provinces and two territories, Autism Society Canada embodies the largest collective voice in the Canadian autism community. In Canada, Autism Spectrum Disorder (ASD) affects over 200,000 individuals and their families yet there is currently no national surveillance mechanism in place to track Canadians living with an ASD. In parts of our country treatment and services for people with ASDs are non-existent. ASC's capacity to connect via our website with individuals in very geographically remote areas makes our web information the only accessible resource within that community. We strongly support universally accessible ASD treatment and services, as well as the implementation of national surveillance.

As the Canadian national autism organisation, we attempt to come to their immediate aid. We point them to regional autism societies who are generally limited in resources and often volunteer lead as they try within a specific province or territory to direct the families to appropriate services. It must be emphasized that appropriate quality of life for individuals living with autism and their families would reduce the cost of services to the provincial health and social service system. We estimate these cost to be more than one billion dollars annually.

ANNEX II

Financial Impact of Autism

Cost were estimated in 2001:

- Lifetime cost per Canadian person with an autism condition \$ 2 million
- Average annual cost per person (based on 70 year lifespan) \$ 29, 000
- Average Canadian annual cost is estimated at more than \$ 3 billion
- New annual lifetime liability for new cases in Canada \$ 60 billion
- Lifetime cost savings are significant when an ASD is diagnosed early, receives accurate and effective treatment, and adequate supports based on best practices.
 - For those who experience significant improvement of their autism condition 25%
 - For all people with autism conditions 50%
- Many people with autism conditions are in care of their province since their families were not able to cope with their care.

Considerations of Autism in Canada

- There have been and are currently a number of lawsuits based on provincial legislation for health, education and social services, and on federal legislation for health (Canada Health Act) and human rights (Canadian Charter of Rights and Freedoms).
- Families caring for a person with an autism condition frequently experience physical and mental exhaustion, which has lead to some tragic actions where parents have taken the lives of their children and attempted to take their own lives as well.
- Parents of people with autism conditions often experience depression, isolation (due to the challenges in taking their child out in public, and from family criticism due to lake of understanding), as well as a higher divorce rate.
- Families are being torn apart by systems that lack understanding and knowledge of the effective and humanitarian treatment of autism within a family.
- Life potential not realised: Without effective early treatment, less than 5% of people with autism conditions are able to proceed in mainstream life. However, with effective early treatment, almost half can precede in mainstream society with minimal support, and probably be able to work and contribute to social programs as taxpayers, repaying the benefits they received.

Additional references:

Autism Documentation in Canada:

2004, ASC developed a Canadian Autism Research Agenda to help shape a Canadian Autism Strategy; copies are available

The bi-partisan senate report from 2007 "*Pay Now or pay Later: autism families in crisis*" outlines the immense economic impact and specific financial burdens that families living with an ASD experience. This report also highlighted 22 key recommendations.

2009 Autism Ontario report: FORGOTTEN: *Ontario* Adults with *Autism* and Adults with Aspergers

Centres of Excellence for Children's' Well-Being: Policy Forum: *Autism Across a Lifespan* – Montreal, 2009

In 2010 Autism Management Team Report on Lifespan needs for persons with ASD in Nova Scotia (released on line Monday May 3) *Creating Respite Solutions for NS Families of children/adult children with chronic high needs.*

Miriam Foundation – Canadian Best Practices

Autism Documentation outside Canada:

Vermont Report on Lifespan needs for persons with ASD

Centre for Disease Control, USA December 2009 – prevalence determined at 1 in 110 children, with boys being 4 to 5 times more likely to be affected.

October 5 2009, *American Academy of Paediatrics Journal* (Kogan, Michael D. et. Al 2009) autism spectrum rates of 1 in every 91 children in America, including 1 in 58 boys.

Autism is the most inheritable disorder (Dr. Peter Gerhardt, *Advances in the science and treatment of Autism*, Dalhousie university conference, November 6-7 2009)

New Zealand Autism Spectrum Disorder – Guideline Summary (Health Ministry, 2008)

Others can be recommended if needed