



Autism Society Canada
Société canadienne de l'autisme

Focus on Change: An Open Letter from Autism Society Canada

June 23, 2006

Autism Society Canada is a nationally incorporated charity founded in 1976 by a group of parents committed to advocacy, public education, information and referral, and the development of provincial and territorial autism societies. Over the last 30 years our mandate has remained constant: to work toward the necessary changes that will improve the quality of life of Canadians with Autism Spectrum Disorders across their lifespan. We would like to take this opportunity to update you on our activities and our community.

There are approximately 200,000 Canadians living with an Autism Spectrum Disorder (ASD) and this figure does not account for the numerous family members and caregivers whose lives are profoundly affected by autism. It is estimated that one in every 166 Canadian children born today has an ASD. We do not yet know the cause(s) but we do know that ASD is more common than Down Syndrome, childhood cancer, cystic fibrosis, multiple sclerosis, blindness and deafness. (For more information about ASD, please visit our website at www.autismsocietycanada.ca).

Over the last two years, we have focused our charitable efforts on increasing awareness and understanding of Autism Spectrum Disorders and on informing and educating the public about the specific needs of our community. (For detailed information, see the attached Appendix: **Service Needs Across the Autism Spectrum Disorder Lifespan.**) We promote current understanding of ASD issues and respect for differences. We are committed to increasing the participation of people with ASD in our community and in our organization. We have an active board member who has an ASD and we have established an Advisory Committee of Individuals with ASD. This committee will hold its first meeting with our Board of Directors this September.

A National Strategy on Autism

Autism Society Canada (ASC) has collaborated with many stakeholders in the national autism community to identify the key components of a national autism strategy. Our communications are focused on this strategy, whether we are writing or meeting with MPs, Senators, their advisors, the media or other interested groups or individuals. We regularly call on government to take a leadership role to address the needs of our community, specifically, to:

- Mandate Health Canada to make autism a national priority by initiating surveillance and reporting, and setting much-needed national standards for treatment, professional training and service delivery across the lifespan
- Increase funding to provinces and territories to provide critical no-cost treatment, education, required supports and accommodations for Canadian children, youths and adults with ASD
- Allocate significant funds for ASD research to Canadian funding organizations such as Canadian Institutes of Health Research (CIHR)
- Improve federal tax and labour supports to people with disabilities and their families

ASC and Advocacy

All of us in the autism community – persons with ASD, parents and other family members, health care professionals, educators and researchers – know that autism has not yet found its rightful place in the health, education and social services systems of our governments. There is much work to be done to increase awareness and understanding of autism, and to promote responsive policies, necessary programs – in the areas of treatment, supports and accommodations – and legislation that will meet the diverse needs of our community.

ASC maintains an ongoing open dialogue with decision makers and stakeholders. As a charitable organization, ASC adheres to government policies for registered charities; we are not free to lobby or petition for change like other non-charitable organizations and individuals can; our activities, including advocacy, must, for the most part, be charitable in nature. We take every opportunity that presents itself to work with our partners, including governments, to increase awareness of the pressing needs of our community and to promote a national autism strategy.

ASC has worked to educate federal officials, MPs and Senators regarding autism. Over the last two years, we have increased our outreach with educational presentations, letters to raise awareness, face-to-face meetings and representation of ASD issues in legal proceedings. Over the last several months, autism has been in the national news; in addition, various motions and private members' bills have been presented in the House of Commons and the Senate has also concerned itself with the needs of our community. We are encouraged by the increased awareness of autism; at the same time, we work to ensure that government recognizes the needs of our community across the lifespan and takes action that will meet the multi-faceted nature of these needs. A national autism strategy is not solely treatment-oriented, although the availability of scientifically validated no-cost treatment (such as Applied Behaviour Analysis) is one of the many important components.

Joining Forces

As a small charity with limited resources, ASC seeks out opportunities to work collaboratively with other groups, organizations and alliances on issues of importance to the autism community. ASC became a member of the Canadian Alliance for Mental Illness and Mental Health (CAMIMH) in 2002 and we have taken an active role in this alliance ever since. CAMIMH's mission is to promote and facilitate the development, adoption, and implementation of a national action plan on mental illness and mental health. Being a member of CAMIMH has helped ASC increase awareness of the needs of our community within a larger community. It has been clear that the federal government would not be addressing mental health issues on a condition-by-condition basis, and has indicated a preference for working with groups of stakeholder organizations. Being a member of CAMIMH has provided ASC with another forum to bring forward our concerns to federal policy makers.

CAMIMH has been very successful in seeking action to address mental health issues across the lifespan of people with various brain-based conditions. In February 2006, a *Framework for Action on Mental Illness and Mental Health*: (<http://www.camimh.ca/frameworkforaction.htm>) was released. Part of ASC's work with our CAMIMH partners has been to ensure that the Framework terminology is inclusive of the autism community. In CAMIMH's Framework, "mental illness" is defined as the spectrum of diagnosable mental illnesses, disorders, conditions and addictions. It is used as an inclusive term rather than using multiple terms repeatedly. While perhaps not perfect, it does recognize that multiple terms for various brain-based disorders and mental health issues are used in

the community. At ASC we believe that this new Framework document is a very workable document addressing many of the issues faced by the national autism community.

Whenever ASC speaks with government officials or politicians, we remind them about CAMIMH's call for a national strategy for mental health, and further explain that such a national strategy must be comprised of strategies for specific conditions, including autism spectrum disorder. ASC has also articulated this view through our White Paper, released in March 2004, entitled *Canadian Autism Research Agenda and Canadian Autism Strategy*. For an electronic copy of ASC's White Paper, please click here: http://www.autismsocietycanada.ca/general_info/download_resources/index_e.html

The May 2006 Senate Report and the June 2006 Senate Motion (Adopted) on Autism

The Standing Senate Committee on Social Affairs, Science and Technology released its final report on mental health issues in Canada on May 9, 2006. The full report, entitled *Out of the Shadows at Last, Transforming Mental Health, Mental Illness and Addiction Services in Canada*, can be found by clicking on: <http://www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/pdf/rep02may06part1-e.pdf>

Contained in the report are 118 recommendations that encompass lifespan issues for Canadians living with mental health challenges. They include many areas that are important for people with ASD, their families/caregivers, and their communities. Two key recommendations are:

- the establishment of a Canadian Mental Health Commission to act as an enabler of a national approach to mental health issues and be a catalyst for reform of mental health policies and improvements in service delivery
- the creation of a Mental Health Transition Fund to provide funding to provinces and territories for projects that would otherwise not have been funded in an effort to accelerate the transition to a system in which the delivery of mental health services and supports is based predominantly in the community

The Senate report includes a very short section on autism and concludes that further study is required in order to do justice to an "extraordinarily complex issue." It further states: "In future, we hope to have the opportunity to undertake a thematic study on autism." We were pleased that the Senate Committee recognized the need for more targeted work on autism.

We congratulate the Senate who yesterday approved the following motion: "That the Inquiry on the issue of funding for the treatment of autism be referred to the Standing Senate Committee on Social Affairs, Science and Technology for study and report; and that the committee submit its final report no later than November 30, 2006." ASC looks forward to meeting with this Standing Senate Committee in the near future to discuss the pressing needs of our community for treatment, supports and accommodations across the lifespan.

ASC supports the establishment of a Canadian Mental Health Commission and the creation of a Mental Health Transition Fund; we believe that the specific needs of our community can begin to be addressed at the national level if these two recommendations are implemented.

Keeping up the Momentum

Changes to include autism as a national priority are long overdue. Autism Society Canada believes that policy makers must build on current momentum and continue to take the steps necessary to help Canada become a leader in autism treatment, service delivery, research and innovation – building solutions and creating new opportunities for people with ASD and their families. We look forward to continuing our work with government, the autism community, our CAMIMH colleagues and all our other colleagues to help change the face of autism in Canada.

Jo-Lynn Fenton, President and Sandra Weizman, First Vice-President
On behalf of the Board of Directors of ASC

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Appendix A

Service Needs across the Autism Spectrum Disorder Lifespan

Autism Society Canada (ASC) supports the development of a national infrastructure for autism treatment and increased service delivery within the provinces. There are currently glaring gaps in the availability of fully funded treatment for children with Autism Spectrum Disorders (ASD), as well as large service gaps for adults and youth with ASD. Need for all of these services will only increase over the coming years since the number of reported cases of ASD has risen steadily over the past decade. There is also a need for increased ASD-specific professional training for service providers (including psychologists and mental health workers, speech pathologists, social workers, educators and others) in order to develop and deliver effective programming and treatment for people with ASD.

Children and Caregivers

Canadian families face an up-hill battle to ensure timely diagnosis and the quality scientifically validated treatment that their children with ASD deserve. Fully funded treatment for children with autism is not yet a reality across Canada and family social support services are non-existent in many areas of our country. Service needs include:

- Implementation of better procedures for rapid screening, diagnosis and assessment
- Timely scientifically validated treatment (such as ABA), services and accommodations for all children with ASD, regardless of age
- Successful education based on published research: implemented education plans, educational supports and accommodations, access to technologies
- Adequate family respite, social, safety and financial supports: ASD often have the most challenging behaviours of any developmental disability and the highest levels of parental stress

Youth and Late Adolescence

People with ASD are particularly vulnerable during youth and late adolescence when the demands of life increase and independence becomes more important. There is a higher than normal level of challenges with depression and anxiety in late adolescence for more able people with ASD. More able does not necessarily mean lower support needs – Autism Spectrum Disorders have a wide range of challenges and needs. In Canada we need more liaison between health, social and education ministries to facilitate the transition from adolescence to adulthood. Needs include:

- Implementation of better procedures for diagnosis and assessment
- Medical and psycho-social support services provided by professionals with ASD-specific training
- More public education to make parents and students aware of autism – Canadians are just beginning to recognize social interaction challenges as disabilities

- More research on the social realities for teens with ASD in the school system. There is a strong association between ASD and bullying/chronic victimization but little is known about the long-term effects or the appropriateness of zero-tolerance policies for youth with ASD
- Supported drop-in programs and social/recreational opportunities for teens
- Support services for transition-aged youth to facilitate increased independence and community integration are vital: life skills development programs, social/recreational opportunities and communication skills development, and programs preparing teens for the workplace.

Adults

Service delivery for adults with ASD, including those who are more able, profoundly affects quality of life. There are higher medical, mental health and psycho-social needs for more able people with ASD, (including such problems as epilepsy, disability, anxiety, mood disorders, etc.). Those who receive active treatment and support (including social skills development, learning support, assisted living and treatment services) most often have a higher quality of life. Needs include:

- Implementation of better procedures for diagnosis and assessment
- Programs across Canada must become more inclusive and accommodate adults and youth (across the lifespan) with ASD
- Supported community and independent living programs for more able people with ASD
- Day treatment programs and part-time programs for adults, including recreational activities, skill training, and individual counselling and case management
- Increased access to appropriate medical and psycho-social services: Diagnosis and treatment for adults requires professional autism-specific knowledge; autism-specific training is also needed for care providers
- Vocational services and supports: skills, job search, workplace supports

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