



Autism Society Canada **Société canadienne de l'autisme**

October 30, 2004

An Open Letter to the Autism Community

As an organization with a 28-year history of dedication to improving the services and opportunities available to people with autism and their families, Autism Society Canada would like to take this opportunity to let our community know more about who we are and the work that we do. Early in the New Year, we will be launching a new website with updated information and a more complete list of resources. We are open to feedback from our community and welcome your suggestions for inclusion of information and resources on our website. Please send your comments, suggestions and feedback to our Executive Director, Louise Fleming, at louise@autismsocietycanada.ca

Who We Are

Autism Society Canada (ASC) is a national incorporated non-profit charitable organization that was founded in 1976 by a group of parents committed to advocacy, public education, information and referral, and provincial development support.

ASC considers people with Autism Spectrum Disorders (ASD) and their parents and families as vital parts of the autism community. Many people with ASD as well as parents of children with ASD have developed considerable expertise about autism. Their first-hand knowledge of the needs and realities of the life of children and adults with autism has made them strong and compassionate advocates for the rights of both children and adults with ASD.

ASC is the national representative for a federation of Canada-wide provincial and territorial autism societies. All provinces and territories except Nunavut have an autism society or equivalent group. Autism societies and their member groups in each region represent the largest group of people with ASD in Canada and most include the active participation of adults with ASD, many at the Board level. ASC's member provincial/territorial autism societies each appoint one representative to ASC's Board of Directors. Lisa Simmermon, the President of ASC, is our primary spokesperson and she can be reached at info@autismsocietycanada.ca. Peter Zwack, first Vice-President and Jo-Lynn Fenton, second Vice-President, are our other spokespersons and they can be reached at info@autismsocietycanada.ca as well.

ASC's Mission and Goals

Autism Society Canada works across the country to support the improvement of ASD research and service delivery as well as the provision of reasonable accommodation. These improvements will, in turn, create better lives and opportunities for all people affected by autism - including children and adults with ASD, their families and their communities. We work to ensure that people with ASD live in an environment that supports their well-being and enables them to reach their full potential as participating members of their communities.

We work at the national level to address issues and concerns common to our membership, the provincial and territorial autism societies, who in turn work on provincial or territorial issues.

What needs to happen to meet our goals?

- Services must be made available and accessible to all who request them;
- Better screening, diagnosis and assessment services for ASD are crucial;
- Effective treatments must be made available universally at no cost;
- Better pro-active family supports and assistance are essential;
- Increased funds for all areas of ASD research are vital;
- More individual supports and accommodating technologies for people with ASD are needed;
- More information about autism and how reasonable accommodation can be provided is necessary.

The objectives of ASC are to:

- Provide a wide range of information and general referrals to the public regarding ASD;
- Promote public, professional and government awareness of ASD;
- Encourage research on ASD;
- Promote activities to ensure people with ASD live in an environment that supports their well-being and enables them to reach their full potential;
- Communicate with government agencies, and other organizations on behalf of persons affected by ASD and their families; and,
- Promote conferences and workshops focused on ASD.

The Role of People with ASD in ASC

Our Board has, historically, been made up predominantly of parents of individuals with ASD because these are the people that our provincial and territorial societies have appointed. Recently, one of our provincial societies appointed a person with ASD to our Board.

ASC, like all voluntary organizations, is working hard to grow and change with the times. We are **involving more people with ASD at the Board level**. ASC is actively encouraging people with autism to be participants not only in their own provincial/territorial autism societies but also at the national level. ASC has created a

Director-at-Large position on our Board for an adult with ASD. We recently filled this position from a list of candidates nominated by our member societies.

In addition to Board representation, **ASC is also in the process of developing a Consultation Group of adults with ASD.** It will be comprised of people nominated by our member societies and chaired by our Director-at-Large. The Consultation Group will act in an advisory role to help ASC work more effectively when speaking to decision-makers about the needs of adults with Autism Spectrum Disorders.

ASC is also hoping to serve adults with ASD better by providing more resources for adults in our new website which is currently under construction. The site will feature expanded resources for university and college students as well as an on-line community forum. Autism Society Canada deeply values the opinions of adults with autism, and continues to be willing to learn, consider ideas and make improved efforts to carry out our work in a respectful and inclusive manner on behalf of all people affected by Autism Spectrum Disorders in Canada.

Care with Terminology

The term "autism" is frequently used as a catch-all term for a wide variety of symptoms, disabilities and special abilities. There is no standard "type" or "typical" person with Autism Spectrum Disorders. There are people with Asperger's or high functioning autism who need little or no special treatment or educational programming, individuals who may enjoy a very high level of functioning and may contribute significantly to the well-being of all. In contrast, there are many families who have children and adults with seriously debilitating autism conditions, who are affected deeply by a myriad of communication, behavioural, sensory and physical problems – children and adults who will need intensive treatment and support to reach their full potential. **ASC tries to advocate for all people with ASD. Due to the spectrum nature of autism, it is important to keep in mind that individuals with autism vary widely in their needs, skills and abilities.**

ASC believes that it is important to distinguish between the clinical terms and descriptions of ASD and our understanding and knowledge of people who live with ASD. Clinical terms are used in medical settings, during diagnosis and in certain treatment settings and it is necessary to understand their use for these purposes. However, it is wise to keep in mind that they may also be seen as limiting labels to people with ASD. We understand that there are people with ASD who may not require or want any kind of treatment. Parts of the autism community feel that autism has been "medicalized" to the point where individuals who are unique in their skills, abilities and value to their communities, have been denigrated, forgotten or eclipsed by the "disorder."

The Right to Treatment

Since without appropriate individualized treatment, many children with autism will not develop effective communication and social skills and may develop serious behavioural problems, ASC believes that early effective treatment, which can lead to great improvement for many people with ASD, should be made available. At ASC we do not believe that any one single treatment or program will benefit **all** people with ASD. Designing individualized effective treatments and programs for children should depend on a careful assessment of the child's profile of strengths and weaknesses, as well as the input from parents and professionals.

Autism Society Canada supports universal access to evidence-based effective treatments for people with ASD of all ages. Governments must not discriminate, and must fund, just as they do for other conditions, effective treatments based on current scientific evidence and recommendations of the individual's medical team. The government should also be ensuring accreditation and adequate training of treatment providers.

The right of choice is paramount, and ASC's efforts are to ensure that all people affected by autism have the possibility of accessing effective treatment and services that they can then choose or decline. The legal actions that ASC supports all deal with the correction of the inequitable application to individuals with ASD of benefits normally afforded to other Canadians. They specifically deal with the rights of individuals with ASD of all ages.

Working Together for a Better Future

As awareness and knowledge increase, parents, families, and people with ASD are demanding better services, education, treatments, vocational opportunities, recreational/social programs, living supports and accommodations. Targeted, accessible services will offer individuals with autism conditions the best chance of improvement and adaptation, enabling them to reach their highest potential.

Like other Canadians with disabilities, people with Autism Spectrum Disorders are becoming more organized and are speaking out about their lives and their rights, and the discrimination they face. Many self-advocacy organizations are providing their expertise, offering speakers for conferences, sharing information and speaking for themselves in the political arena. There are also an increasing number of support groups run by and for adults with autism, both on-line and in support group settings around the country. First-hand insights into the challenges of living with this complex disability and the unique knowledge now being shared among people with autism, their families and professionals, will likely have a profound effect on the future development of autism treatments and the continued development of both family and adult supports.

Lisa Simmermon and Peter Zwack
On behalf of the Board of Directors of ASC