

## **FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers**

### **EXECUTIVE SUMMARY**

Why have adults with Autism Spectrum Disorder (ASD) been forgotten and how can we work together to help these individuals across the entire spectrum to have the best possible quality of life?

With this discussion document, Autism Ontario will illustrate why the recommendations put forth matter to all Ontarians.

At this time, there is no consistent government policy regarding the need for supports and services for adults with Autism Spectrum Disorder (ASD), nor agreement of which ministry/ministries should be involved in funding those services. Further, there is no “generic” system of adult services for those people with Aspergers to fall back on, unlike the developmental services sector that supports those with a cognitive impairment. Most, if not all individuals with autism, require some care, supervision or support through their entire lives; many require a great deal. Families and caregivers are not getting the help needed to plan for services and supports for a future when they are no longer here to be advocates for their loved ones.

### **Everyday Barriers**

Individuals with ASD exhibit a wide range of behavioural challenges stemming from difficulty in verbalizing thoughts, managing anxiety, dealing with change, participating in group activities, disengaging from discussions on a specific topic—all leading to problems in coping with everyday activities. Not surprisingly, some individuals also have a diagnosis of mental illness. Autism Spectrum Disorder, developmental disability and psychiatric illness are separate conditions, yet much of the current service system is geared towards supporting individuals with an intellectual disability— leaving many adults with ASD without appropriate support.

### **Prevalence and Impact**

The list of recommendations of policy and funding changes for adolescents and adults with autism made in the 1991 report, “*Our Most Vulnerable Citizens*” are still valid today (ASO, 1991).

Sadly, people with autism remain among our most vulnerable and most poorly served citizens.

If we fail to address this issue, costs will be enormous. Using the figures from a US study (Ganz, 2007) the cost for a single generation in Canada could range from \$1.4 to \$8.4 billion CDN. This can be reduced substantially by providing appropriate and needed supports.

The current framework and funding to support the specific needs of this population have barely begun to have an impact on the needs and numbers of the estimated 70,000 individuals affected in Ontario, 50,000 of whom are adults (*ADDMNS, 2002*).

### **Supports and Challenges**

While families whose children are making the transition from teen to adulthood may expect to find similar levels of services in place for adults as were experienced with the school system, this is not the case. First, current services (i.e. developmental services) for adults are designed for people with an intellectual disability.

In some parts of the province, individuals with IQs greater than 70 are routinely excluded from such funding and supports.

Secondly, developmental service providers often do not have the knowledge or training to deal with the unique, complex and highly individualized needs of adults with ASD.

### **Research and Best Practices**

Unfortunately, there is a paucity of peer reviewed literature discussing programs, education and counselling for adults with ASD. There remains a need for dedicated research on adults on the autism spectrum.

The establishment of consolidated best practices “knowledge exchange centres” was recommended in the Standing Committee on Social Affairs, Science and Technology report, yet there has not yet been any forward action (*Standing Committee on Social Affairs, Science and Technology [SCSAST], 2007*).

### **RECOMMENDATIONS**

The current framework of care does not match the complex, ongoing needs of adults with ASDs. This approach is piecemeal and out of date and, as a result, the services provided are not satisfactory. Both specialized services and enhanced community service capacity are needed to meet the service needs of the adult ASD population. Collaboration is needed to establish and champion an Ontario-wide policy framework and coordinate the service delivery approach for adults with ASD.

Autism Ontario stands ready to provide provincial leadership in partnership with the Government of Ontario. We urge all Ontario Ministries to work together with us to make it happen.

These are our recommendations:

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### **Recommendation One**

Ensure sufficient and regulated services for adults with ASD in the adult/child mental health, social service, colleges/universities and developmental sectors through an Ontario-wide cross-sector policy framework and devoted funding based on a provincial needs assessment. Specifically, this policy framework would ensure:

- a) Financial supports which are not tied to “claw-backs” through ODSP, Registered Disability Savings, and welfare programs;
- b) Day supports including vocational and employment, educational, social and recreational services/ opportunities;
- c) Programs devoted to monitoring the well-being and safety of adults with ASDs;
- d) A range of supported living options; and
- e) Professional supports including psychological, medical, and psychiatric assistance, dental care, person-centered planning, case coordination, respite care, crisis supports and legal assistance.

### **Recommendation Two**

Implement standard eligibility criteria to services for adults with ASD based on their functional needs rather than intellectual functioning through an Ontario-wide cross-sector policy framework.

### **Recommendation Three**

Facilitate access to best practices education and research specific to adults with ASD across adult/child mental health, social service, colleges/universities and developmental sectors through a provincial knowledge exchange centre. This centre would:

- a) Lead a provincial needs assessment;
- b) Guide or seed, translate and disseminate best practice research;
- c) Provide information to specialized and generic or developmental service providers;
- d) Provide information to families and individuals with ASDs; and
- e) Track adult services available throughout the province.

## **Next Steps**

This report has focused on adults with autism and adults with Aspergers in Ontario: the economic impact, a review of existing supports and services, and a look at the state of research and best practices.

The facts are disconcerting—namely, that the growing costs to healthcare, social services and the education system, along with lost productivity of individuals with autism and their parents and siblings are substantial. There is a significant need for dedicated research and consolidation of best practices. The majority of adults with ASD do not have access to the specialized services and enhanced community services that they need. For example, people with ASD face a scarcity of available services and supports when they become adults.

Furthermore, their families and caregivers do not receive services and supports that they need to help plan for their child's future when they are no longer able to advocate for them.

Clearly, the current framework of care does not match the complex, ongoing needs of adults with ASD. Collaboration is needed to establish and champion an Ontario-wide policy framework.

Now is the time to make the recommendations made in this document a reality.

(For an electronic copy of this report, or for more information on adults and ASD, visit: [www.autismontario.com](http://www.autismontario.com))

## **What is Autism?**

Autism is a complex developmental disorder that affects the function of the brain.

The term autism spectrum disorders (ASDs) describes a group of disorders (Autism, Aspergers and atypical Autism or PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified)) with the same symptoms: impaired communication and social interaction and repetitive behaviours and restricted interests. The range of disability resulting from these symptoms can be mild to extremely complex since the symptoms present in a variety of combinations. As a result, each person is affected uniquely. A combination of specialized supports is needed in social and communication skills, in carrying out daily living skills and in employment venues. (See Appendix B for ASD sub-types).

In Ontario, there are an estimated 70,000 people with ASD, 50,000 of whom are adults (*Autism and Developmental Disabilities Monitoring Network Surveillance [ADDMNS], 2002*).