



Adults with Autism

- How Many Adults Have Autism Spectrum Disorders
- Why Don't We Hear About Adults?
- What About the Needs and Abilities of Adults with Autism?
- What Factors and Strategies Lead to Best Outcomes for Adults?
- Towards Better Lives and More Secure Futures for Adults with ASD
- OAARSN Resources for Learning More

Autism Among Ontario Adults

How many are affected? In comparing data of the prevalence of autism, we should note its definitions have been widened. "Classic" autism or Kanner Syndrome, identified just 60 years ago, affected 4.5 in 10,000 in all racial and socio-economic groups. By the mid-1980s, pervasive developmental disorders or PDD affected about 20 per 10,000. A broader concept of Autism Spectrum Disorders (ASD) by the late 1990s, including also Asperger Syndrome, means that one per cent or more of the population may be affected.

Has autism actually increased? Research into genetic, environmental and biomedical factors is not yet able to answer this question. Two important factors are the broader concept and the enormous increase in general awareness, so that professionals and parents recognize the symptoms of ASD much more readily than they did a generation ago.

Statistics of adults diagnosed with autism and related disorders are not available in Ontario. This table estimates the numbers in age-groups, based on ratios found in other epidemiological surveys. We used a more conservative rate for ASD than in some current estimates.

Ontario Estimates (2001 Census)

Age group	"Classic" 1 in 2,222	ASD rate 1 in 150
0 - 4 years	302	4,473
5 -14 years	702	10,407
15-19 years	346	5,127
20-24 years	323	4,787
25-44 years	1,583	23,453
45-54 years	736	10,900
55-64 years	479	7,093
65 + years	662	9,813
Children (0-19)	1,351	20,007
Adults (20+)	3,784	56,060

Why Don't We Hear About Adults?

A generation ago, almost nobody knew about autism except the tiny proportion of families whose children were diagnosed. Now autism is always in the news, especially the service needs of young children. Have adults outgrown their autism or recovered? No...

Only a tiny number of Ontario adults diagnosed with ASD have appropriate supports to lead good and fulfilling lives in their communities. Some younger and middle-aged adults may have pretty good lives because of the dedication of their parents.

Almost all suffer from general assumptions that they have a poor prognosis as adults. Professionals and policy-makers do not think that they are worth much in resources.

Most adults diagnosed with classic autism were not supported to develop communication and social skills and may have poor daily living skills. There are almost no resources to help them to continue learning.

Too many have restricted lives in custodial care with no support for their autistic disabilities. Some are incarcerated with no social contact and some die tragic deaths. Professionals, agencies and caregivers may see autistic adults as mainly challenging because of their severe behavioural problems.

Most adults who probably had the symptoms of ASD in early childhood were not detected, or were given other labels, perhaps with "autistic tendencies." Those who were not diagnosed at all may have had social and learning difficulties in the school years and, as adults, discover or suspect they have Asperger's or high-functioning autism (HFA). But they can seldom get help.

Autistic adults who live without support may be reclusive or eccentric; they may be labeled with various mental health disorders and at risk for severe depression and suicide.

What have we learned of the needs and abilities of adults with autism?

Autism is highly complex and affects each person in a unique combination of ways. Its multiple causes are not yet fully understood.

Autism involves disorders of the brain, neuroimmune and gastrointestinal systems. The central impairment shared by people with ASD is general difficulties with social communication and relationships. Other symptoms may include hypersensitivities and reactions to any or all sensory stimuli, inability to speak or other difficulties with language, intolerance of various foods and drugs, sleep disorders, seizures, low muscle tone, movement differences, unusual fears, and obsessions with routines and order. The presence and severity of these symptoms varies in individuals. Those most severely affected may express their pain and frustration in behaviours that can hurt themselves and others.

A distinctive feature of people with ASD is the unevenness of abilities and disabilities. While their development is affected by their disorders, they are not necessarily intellectually handicapped. Some who cannot speak can express mature and insightful thoughts when given the chance to communicate in other ways. Some people with ASD are highly intelligent and some have remarkable abilities in special fields including music, art, numbers, computers, and spatial reasoning. But these special abilities are at odds with their practical and social disabilities.

Whatever their original symptoms, autistic adults may also bear the scars of faulty assessments and less-than-optimal treatment in the childhood and early adult years.

Perhaps the greatest difficulties are the barriers raised by other people's perceptions, attitudes and expectations.

What factors and strategies, starting in the school years, lead to best outcomes for adults with ASD?

- Strategies based on observations of “what helps?” as well as on assessments of “what’s wrong?” A focus on abilities more than on deficits. .
- Respect for loving families as the experts on their daughters and sons with ASD and for their uniquely valuable experience and sense of responsibility.
- A personal support network of friends of all ages who care and share time and interests.
- Plans and strategies that consider each person as an individual. The more complex the disorder, the more individualized the supports must be
- Constructive co-operation among all involved, to meet the needs and abilities of each person with ASD, including, as needed:
 - Support to communicate thoughts and choices and to interact with others, in ways that work for each person
 - Structured, predictable and familiar environments and routines, adapted as needed to suit each person
 - Recognition of and help to cope with sensory stresses and transitions
 - Work and recreational-leisure activities that give a sense of accomplishment and being valued
 - Opportunities to continue learning
 - A safe and caring home supported by companions one chooses
 - Adequate and sensitive healthcare services
 - Access to all necessary resources and expertise
- Advocates to ensure that rights and needs are respected and not violated, and that existing services are appropriate and adequate

Towards Better Lives and More Secure Futures for Adults with ASD

Start early, even from childhood, and keep evolving these interrelated strategies. Find more information about these good ideas and practices on the OAARSN website.

1. Encourage self-expression and choices by whatever means. See the humanity, abilities and potential in your son/daughter, however severely challenged. "Listen" to them (even when they do not speak) to understand their point of view and priorities. Observe and record what strategies work best.
2. Find and keep friends of various personalities, ages and abilities, who get to know the person very well and can support and continue the parents' roles. Friends can support one another as well as the person when organized as a Circle or Personal Support Network. Adults with ASD needs friends and allies in addition to family and those who are paid to be in her/his life.
3. Plan with the person
Planning tools developed by Inclusion, such as PATH (Planning Alternative Tomorrows with Hope), MAPS and CIRCLES, are helpful in working through transitions, envisioning a good life and devising strategies to attain it.
4. Be creative and flexible in setting up key parts of the person's plan for a good life
Don't be limited by the traditional service system. Consider what's really needed and find ways to make it happen. Have a clear understanding of your general goals. But also be open to the opportunities, even serendipity, at some unexpected turns in the PATH.
5. Consider the best kind of living situation for each person. Adults with ASD need choices. A person with hypersensitivities may need her/his own home, supported in the ways s/he needs and shared

with companions s/he chooses. Guelph Services for the Autistic (GSA) is pioneering a model of home ownership that includes choice and self-direction by the person, longterm capital investment by the family, support circles and networks, and recruitment and matching of homesharers and volunteers.

6. Daily activities must be real and fulfilling and include continued learning, healthful exercise, and contributions to the community

Each person should have a way of life that is uniquely suited to her/his needs and interests. S/he should be able to comment and make requests and suggestions. Support workers should be chosen by the focus person and carry out their wishes.

7. A good life must be sustained, beyond the lives of parents.

A new mechanism is the aroha, an incorporated entity of personal empowerment and support (like a microboard in British Columbia). An aroha can give good friends of the person and parents the legal powers to strengthen and continue family efforts. An aroha can own property, and receive and manage resources to match needs and wishes.

Some Resources from the Ontario Adult Autism Research and Support Network

<http://www.ont-autism.uoguelph.ca/>

OAARSN offers a collection of up-to-date information and communication tools, with opportunities for mutual support and encouragement among adults with autism, family members, caregivers, friends, support workers, teachers, administrators and policymakers. The focus on adult issues balances the emphasis on autism in children in most other Internet resources. Adults with autism deserve better supports and quality of life than they are getting.

From OAARSN's main page, use the buttons to explore the website's features. You may ask to be added to the OAARSN Listserv to receive weekly bulletins of autism news, announcements of events, and new content added to the OAARSN site.

Keep up with new Books on the Autism Spectrum.

Use the OAARSN Search function to learn more about creative strategies such as aroha, PATH, MAPS, CIRCLES, personal support networks, inclusion, homeownership, homesharing, micro-enterprises, person-centred planning, individualized funding.

Use the Discussion Board to ask questions, share experiences, start threads of discussion.

Complete our Adult Needs Survey.

Read about the ASPIRE project that seeks to empower persons with autism and their families and friends to create good lives and secure futures. Find our poster of "Ten Steps to Realize a Personalized Plan".

Read valuable pages From the Frontlines, like Isaac's Story and Ontario's First Aroha.

Leaflet by Elizabeth Bloomfield of the OAARSN team as a public service.