

**Autism Ontario
Ontario Partnership for Adults with Aspergers and Autism**

**Response to the
Minister of Community & Social Services**

**Ontario Regulations:
Services and Supports to Promote the Social Inclusion of Persons with
Developmental Disabilities Act, 2008**

About this Submission	2
Discrepancies Between Regulations and the Wording of the Act.....	2
Inappropriate Reliance on Standardized Intelligence Tests for Eligibility	3
Inadequate Definition of Qualifications for Individuals Determining Eligibility	4
Limits to Individual Choice	4
Failure to Fully Protect Vulnerable Individuals in Housing Environments.....	5
Conclusions	6
Recommendation Summary	6
Appendix	6

About this Submission

In 2008, Autism Ontario welcomed the opportunity to make a submission on “Bill 77, An Act to Provide Services to Persons with Developmental Disabilities, to repeal the Developmental Services Act, and to amend other statutes”. From these submissions the Bill became law as the “Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008”, an encouraging change of title reflecting a new era of acceptance. We are pleased to provide input on the draft regulations concerning this Act.

The comments and recommendations in this document are based on numerous meetings of an Autism Ontario working group, input from the Ontario Partnership for Adults with Aspergers & Autism (OPAAA) and consultations with our province-wide membership.

In this submission, the term “family” is used broadly. Legal familial ties are subject to change over the lifespan of an adult with a developmental disability, so “family” should be read as representing families, caregivers, guardians or others with a vested interest in supporting and representing the needs and interests of the individual.

Discrepancies Between Regulations and the Wording of the Act

We feel that in several critical areas the regulations, in both their plain language and full form, express intentions that are contrary to both the provisions and spirit of the Act. Further, the plain language version, which is intended to help clarify the regulation, in fact further limits it, to an alarming degree.

Definition of “Developmental Disability”

The Act (Part 1, Section 3) defines “developmental disability” related to “*significant limitations in cognitive functioning and adaptive functioning*” that “*affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity*”. It further defines adaptive functioning as “*a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills*” and cognitive functioning as “*a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgements and identify consequences*”. This set of definitions not only met with Autism Ontario’s approval, but also reflected a progressive model of social inclusion.

The regulations, however, in sections 2 and 3, define cognitive functioning in terms of relative performance on “*a standardized intelligence test*”. Although the definitions do allow cognitive functioning to be assessed “*on the basis of a clinical determination made by a psychologist or a psychological associate*”, this is restricted to cases where an individual has **both** “significant limitations in cognitive functioning” and “a history of habilitative support needs”.

We are deeply concerned about this move to a medical definition of disability, a model that fails to support the aims of social inclusion.

RECOMMENDATION:

ENSURE REGULATIONS ALIGN WITH THE ACT, RETURNING TO THE ORIGINAL DEFINITIONS OF COGNITIVE AND ADAPTIVE FUNCTIONING.

Origins of Developmental Disability

Although the Act (Part 1, Section 3) says only that the developmental disability must have “*originated before the person reached 18 years of age*” and be “*likely to be life-long in nature*”, the regulations introduce a concept of “habilitative support needs”. These needs are explicitly defined as caused by “*congenital injury or disease or injury or disease acquired early in life*”. The plain language form of the regulations, possibly inadvertently, removes the cause of congenital disease in its definition (“*People need these supports because of an injury at birth or before birth, or by an accident or illness that happened early in life*”). Many forms of developmental disability are neither an “injury” nor a “disease”, in conventional definitions. It seems unlikely that the intent of the regulations is to exclude individuals with such conditions, including ASD (which is present at birth and pervasive in nature), but those are the implications of the guidelines as written.

RECOMMENDATION:

ENSURE REGULATIONS ALIGN WITH THE ACT, REMOVING REQUIREMENT FOR SPECIFIC CAUSES OF THE DEVELOPMENTAL DISABILITY.

Inappropriate Reliance on Standardized Intelligence Tests for Eligibility

We acknowledge the need for standardized methods of assessing eligibility for service and support, but are deeply concerned with the limited way in which these are described. Although the regulations, in their definition section, refer generally to standardized tests, only “standardized intelligence tests” are explicitly identified as part of the eligibility criteria. The plain language version goes even further, replacing “intelligence tests” (which, arguably, could encompass several different types of tests) with the very specific “IQ test”. Furthermore, the relative measurements outlined in the regulations (“two standard deviations below the mean”) are represented in the plain language version as a specific IQ test score (“70 or less”).

Intelligence and adaptive behaviour tests, however scientifically valid, are far from adequate in assessing all the issues that affect an individual’s need for supports. Traditional, but narrow, concepts of “intelligence” as measured by tests such as the Wechsler series are not valid for the purposes of these regulations. The current research literature includes, in the definition of intelligence, broader concepts such as social and emotional intelligence. Scores on intelligence tests, if used at all, should be considered only one factor in determining eligibility.

Assessments should rely on tools that can assess a comprehensive range of issues, including cognitive strengths and weaknesses, mental health, social skills, executive function, life skills, problem behaviours, quality of life, and support needs. They should also take into account the wealth of knowledge and experience held by the family and others who work intimately with the individual being assessed. Standardized tests should not be relied on so heavily.

Reliance on the requirement for limitations in both cognitive and adaptive functioning may result in unfairly inhibiting access to support for individuals who truly need it in order to achieve social inclusion. In particular, the literal application of these regulations may have the effect of excluding many individuals with ASD, particularly those with a diagnosis of Aspergers or High Functioning Autism. It is important to note that Aspergers (also known as Asperger’s Disorder or Asperger Syndrome) is deemed, in the DSV-IV, a “Pervasive Developmental Disorder”. Individuals with Aspergers may have a history of impaired interactions, communication dysfunction, and challenging behaviour

without significant cognitive impairments. That in no way decreases or removes their need for supports. In fact, these challenges, including difficulties with planning, organizing, identifying risk, moderating emotions, decision making and flexibility, affect all facets of an individual's life. They often result in immense disability and resultant mental health issues, including serious consequences such as hospitalization or incarceration.

Additional concerns about standardized testing include:

- Who will pay the costs?
- Can existing assessments be used?
- How can testing be ensured to be culturally competent, respecting diversity?
- Where will the testing would take place? (This is particularly a concern to people in rural areas, where assessment might be available only through local agencies who would, therefore, be in a conflict of interest.)
- How easy will it be for non-English speakers to get assessments in their native language?

**RECOMMENDATION:
EXPAND CONCEPT OF “STANDARDIZED TEST” TO INCLUDE ANY PROPERLY
RECOGNIZED, RELIABLE TEST THAT HAS BEEN VALIDATED FOR USE WITH
INDIVIDUALS HAVING A SPECIFIC DEVELOPMENTAL DISABILITY.**

**RECOMMENDATION:
MODIFY THE REGULATIONS (WHOLE AND PLAIN LANGUAGE VERSIONS) TO
REMOVE DIRECT REFERENCES TO INTELLIGENCE OR IQ TESTS.**

Inadequate Definition of Qualifications for Professionals

Standardized tests rely heavily on the skills of the individual administering them. Notwithstanding the definition of psychologists and psychological associates under the Psychology Act, professionals entrusted with the responsibility to assess eligibility for services must have demonstrated experience and competencies in the assessment and diagnosis of individuals with significant limitations in cognitive functioning and who present with mental health needs and/or challenging behaviours. The unique needs of individuals with ASD are still not well understood by many professionals and agency staff in the Developmental Services Sector. With a current prevalence rate of 1 in 150 children born having ASD, more specialized training in ASD is required of such professionals. These professionals must also gain increased familiarity and experience in the various manifestations of autism. When dual diagnosis is considered, the requirement for specialized training becomes even more critical.

Another important area of concern is the Supports Intensity Scale, which plays a huge role in planning services and supports and must not be excluded.

**RECOMMENDATION:
EXPLICITLY ADD TO REGULATION THE REQUIREMENT THAT
PSYCHOLOGISTS AND PSYCHOLOGICAL ASSOCIATES ASSESSING AN
INDIVIDUAL WITH ASD HAVE DEMONSTRATED EXPERIENCE AND
COMPETENCY IN ASD.**

**RECOMMENDATION:
EXPLICITLY ADD TO REGULATION THE REQUIREMENT THAT**

PSYCHOLOGISTS AND PSYCHOLOGICAL ASSOCIATES CONSULT WITH OTHER PROFESSIONALS AND NON-PROFESSIONALS INVOLVED WITH THE AFFECTED INDIVIDUAL.

Limits to Individual Choice

The Act was embraced widely as a critically important move to direct funding (where the individual's support system is able to administer such funds), a model that provides a full range of choices to individuals and their families, and demonstrates a respect for them as full participants in society. Excluding residential services and professional and specialized services from the direct funding service model (an exclusion not made in the Act) arbitrarily and unfairly limits those choices. This limitation is particularly inappropriate for individuals with ASD, whose multi-faceted challenges require a range of housing options and professional involvement. Professional services should include a wide range of services, including but not limited to those provided by speech pathologists, psychologists, psychiatrists, occupational therapists, behavioural therapists, etc.

**RECOMMENDATION:
INCLUDE RESIDENTIAL SERVICES AND SUPPORT AND PROFESSIONAL/SPECIALIZED SERVICES AS DIRECT FUNDING OPTIONS.**

**RECOMMENDATION:
REQUIRE OTHER MINISTRIES RESPONSIBLE FOR SOCIAL HOUSING TO FUND INCENTIVE PROGRAMS TO DEVELOP RESIDENTIAL OPTIONS AND PROFESSIONAL/SPECIALIZED SERVICES IN RURAL AREAS WHERE THESE ARE LIMITED.**

Failure to Fully Protect Vulnerable Individuals in Housing Environments

Inadequate Protections in Private Homes

The regulations provide for no accountability for those receiving assistance under the Act while living in a private home. The finding of manslaughter in the recent death of Tiffany Pinckney, a young adult with ASD left in the care of her family without monitoring, spotlights the importance of such a mechanism.

Inappropriate Focus on Privacy and Physical Premises

The provision of two weeks notice for inspections seems to place more emphasis on protecting privacy than on protecting vulnerable people.

The overall provisions appear to be more concerned with the physical premises than the well being of the people living there. Inspections should be triggered by, and include, feedback from, residents, their families and circles of support.

An official should be able to enter the home (whether supported group living resident, intensive support resident, or private home) of an adult with a developmental disability whenever there is reasonable evidence of wrong doing or serious neglect in the home. However, this should be balanced with the rights of individuals not to be disrupted by inspections or other intrusions into their homes without valid reasons.

**RECOMMENDATION:
ALLOW OFFICIALS ACCESS TO ANY HOUSING SITUATION, ON REASONABLE SUSPICION OF WRONGDOING OR SERIOUS NEGLECT.**

Conclusions

Although Bill 77 was a strong indication of a positive future for adults with developmental disability in Ontario, serious flaws in the recommendations (and their presentation in plain language form) must be rectified if those individuals are to achieve true social inclusion.

Recommendation Summary

ENSURE REGULATIONS ALIGN WITH THE ACT, RETURNING TO THE ORIGINAL DEFINITIONS OF COGNITIVE AND ADAPTIVE FUNCTIONING.

ENSURE REGULATIONS ALIGN WITH THE ACT, REMOVING REQUIREMENT FOR SPECIFIC CAUSES OF THE DEVELOPMENTAL DISABILITY.

EXPAND CONCEPT OF “STANDARDIZED TEST” TO INCLUDE ANY PROPERLY RECOGNIZED, RELIABLE TEST THAT HAS BEEN VALIDATED FOR USE WITH INDIVIDUALS HAVING A SPECIFIC DEVELOPMENTAL DISABILITY.

MODIFY THE REGULATIONS (WHOLE AND PLAIN LANGUAGE VERSIONS) TO REMOVE DIRECT REFERENCES TO INTELLIGENCE OR IQ TESTS.

EXPLICITLY ADD TO REGULATION THE REQUIREMENT THAT PSYCHOLOGISTS AND PSYCHOLOGICAL ASSOCIATES ASSESSING AN INDIVIDUAL WITH ASD HAVE DEMONSTRATED EXPERIENCE AND COMPETENCY IN ASD.

EXPLICITLY ADD TO REGULATION THE REQUIREMENT THAT PSYCHOLOGISTS AND PSYCHOLOGICAL ASSOCIATES CONSULT WITH OTHER PROFESSIONALS AND NON-PROFESSIONALS INVOLVED WITH THE AFFECTED INDIVIDUAL.

INCLUDE RESIDENTIAL SERVICES AND SUPPORT AND PROFESSIONAL/SPECIALIZED SERVICES AS DIRECT FUNDING OPTIONS.

REQUIRE OTHER MINISTRIES RESPONSIBLE FOR SOCIAL HOUSING TO FUND INCENTIVE PROGRAMS TO DEVELOP RESIDENTIAL OPTIONS AND PROFESSIONAL/SPECIALIZED SERVICES IN RURAL AREAS WHERE THESE ARE LIMITED.

ALLOW OFFICIALS ACCESS TO ANY HOUSING SITUATION, ON REASONABLE SUSPICION OF WRONGDOING OR SERIOUS NEGLECT.

Appendix

About Autism Ontario

Autism Ontario is the leading source of information and referral on autism spectrum disorder (ASD) and one of the largest collective voices representing the autism community. The association and its 30 chapters throughout the Province of Ontario share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community. We are dedicated to

increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact.

Our Vision: Acceptance and opportunities for all individuals with Autism Spectrum Disorders

Our Mission: To ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society

Autism Ontario Working Group for this paper:

Lynda Beedham, Ethel Berry, Eileen Cole, Heather Fawcett, Patricia Gallin, Barb Gjos, Lyn Kyneston, Laurie Pearce, Margaret Spoelstra, Jonathan Weiss, Howard Weinroth

About OPAAA (Ontario Partnership for Adults with Aspergers and Autism)

We are a distinct, collective voice for the needs of adults with ASD in Ontario. We primarily meet and speak with government leaders and parents on matters related to adults on the autism spectrum.

Members include:

- Patricia Gallin & Howard Weinroth, co-chairs
- Lynda Beedham, parent
- Ethel Berry, Autism Ontario
- Gerry Bloomfield, Ontario Adult Autism Research & Support Network
- Nancy Cherry, parent
- Eileen Cole, family member
- Dr. Jeanette Holden, ASD researcher
- Rick Ludkin, Woodview Manor
- Stephanie Moeser-Warren, Geneva Centre for Autism
- Dale Munro, Regional Support Associates
- Margot Nelles, Asperger Society of Ontario
- Glenn Rampton, Kerry's Place
- Doug Reynolds, parent
- Sylvia Sikakane, Geneva Centre for Autism
- Margaret Spoelstra, Autism Ontario
- Dr. Kevin Stoddart, ASD Clinician
- Dr. Peter Szatmari, ASD researcher
- Natalie Whatley, parent

Relevant Resources

FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers

Recommendations for supports and services for adults with Autism Spectrum Disorder;
Autism Ontario, 2008

[http://www.autismontario.com/Client/ASO/AO.nsf/object/Forgotten+Report+Autism+Ontario/\\$file/Forgotten+Report+Autism+Ontario.pdf](http://www.autismontario.com/Client/ASO/AO.nsf/object/Forgotten+Report+Autism+Ontario/$file/Forgotten+Report+Autism+Ontario.pdf)

Protecting Vulnerable Adults: Lessons from the Past, Recommendations for the Future

A community discussion process focused on the protection of adults who are vulnerable to abuse and neglect;

Human Services Consultants, November 2008

<http://www.kerrysplace.org/Latest%20News/Vulnerable%20Adults%20Dec.10%202008.pdf>

Every Door is the Right Door

Towards a 10-Year Mental Health and Addictions Strategy, A discussion paper;

Ministry of Health, July 2009

http://www.health.gov.on.ca/english/public/program/mentalhealth/minister_advisgroup/pdf/discussion_paper.pdf