



Autism Ontario
Ontario Partnership for Adults with Aspergers and Autism
Comments to the
Minister of Municipal Affairs & Housing
Ontario’s Long Term Affordable Housing Strategy

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About this Submission

Autism Ontario welcomes the opportunity to contribute to the discussions concerning long-term housing in Ontario. Although some aspects of housing for individuals with ASD (Autism Spectrum Disorder) fall under the domain of other ministries, it is critically important that any new strategies for housing do not place additional barriers between the members of our diverse population and the housing they desperately need. For individuals with ASD, as with any other group of citizens requiring support to meet their housing needs, it is critically important to be recognized as valuable contributors to our society, and given every opportunity to be integrated into that society.

About ASD

Autism is a complex developmental disorder that results in impaired communication and social interaction, repetitive behaviours, and restricted interests. The term “autism spectrum” has been adopted to reflect the wide range of disability affecting individuals with ASD. Whether individuals are affected mildly, severely, or somewhere in between, they all have difficulty verbalizing thoughts, managing anxiety, dealing with change, participating in group activities, and disengaging from discussions on a specific topic. These symptoms make coping with everyday life a struggle for the estimated 70,000 Ontarians with ASD. Given their challenges, it is not surprising that some people with ASD have an additional diagnosis of mental illness.

For more descriptive information regarding adults on the autism spectrum, see Autism Ontario’s paper “Forgotten”. (FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers, Autism Ontario 2008.) www.autismontario.com

Housing Challenges for Individuals with ASD

Although their symptoms and characteristics change over time, the approximately 50,000 adults with ASD in Ontario need a range of supports for their whole lives. Housing is an important part of that support structure, and one that is particularly troubling for aging parents and overly stressed families. For many individuals with ASD, the only thing standing between them and homelessness is their family. However, families are not always able to safely cope with the behavioural challenges of their loved ones.

For most adults with ASD, housing options are scarce. Supportive housing options for adults with developmental disabilities may be an option for individuals more severely affected by ASD, although not for those who are less affected. However, the lengthy waiting lists put additional pressures on families. Some individuals with ASD receive crisis housing, although this solution can raise more problems than it solves, given the great difficulties individuals with ASD have when dealing with change and uncertainty.

More able individuals with ASD either do not qualify for, or would not benefit from, conventional supportive housing arrangements. Housing options for these individuals are scarce, leaving them struggling to contribute to their community and achieve a reasonable quality of life independent from their families.

Adults with ASD often rely on ODSP for their daily living costs. However, ODSP does not cover the cost of market value housing, in most communities covering only the costs associated with shared or social housing. For individuals who have severe difficulties living with others, particularly others who do not share their interests or experiences, this limitation poses a severe hardship. Housing subsidy programs that might offer a solution are under-funded, with lengthy waiting lists.

Housing Challenges for Families of Individuals with ASD

Families that include children, youth, or adults with ASD can face serious financial and personal restrictions. When the affected individual requires a high level of care (and/or publicly funded supports are inadequate or non-existent) full employment for at least one parent may not be possible. Families in this situation need to be considered eligible for affordable housing programs.

Suggested Solutions to the Challenge

Develop incentives and innovative solutions for families

Despite the services available in Ontario, parents of individuals with ASD remain primarily responsible for caring for, advocating for, and supporting their adult children. Parents who have devoted their lives to doing whatever is necessary to ensure success for their affected family member(s) are willing to turn their energies to the considerable challenge of housing those individuals. However, they should not be expected to do this alone. Incentives such as 0% mortgages, down payment grants, funding to assist with renovations, family-directed funding, and the removal of barriers to innovative and flexible housing alternatives are just some of the ways the government can help.

Provide support for navigating the current housing system

For individuals who qualify for support programs such as rent subsidies, the complexity and bureaucracy involved in accessing the programs is often a barrier. Many do not have the capacity to fully understand and respond to the complex rules and requirements without guidance, and the expertise to provide that guidance is often beyond the ability of the family. However, individuals who require subsidies may not qualify to receive service from agencies who could help them navigate through the system. Agency-neutral services need to be available to help individuals with ASD navigate the housing system.

Expand the definition of “supportive housing”

The definition of “supportive housing” needs to be expanded to include options that meet the needs of a broad range of the ASD population, not just those with more severe symptoms. Consultation with parents is vital, since they best understand the unique combination of strengths and needs of their loved ones. For example, some individuals would benefit from an “inter-dependent living” arrangement with peers who have similar life experiences and interests. The lack of social competence in individuals with ASD does not represent a lack of social interest – inter-dependent living allows individuals who are capable of living independently a much-needed opportunity to engage socially.

Ensure support staff are knowledgeable

Increasing the number of affordable housing spaces and the number of rent supplements is critically important, but is not sufficient to address all the needs of the ASD population. Without support staff who are knowledgeable about the unique challenges of ASD, and without being situated within a supportive, inclusive community, the housing placement is likely to fail. Service managers and housing providers need to be encouraged to look at broader issues or patterns and be empowered to develop flexible, creative solutions. Providers of supportive housing for individuals with ASD need to be provided with a mechanism for the collaborative exchange of resource information, training opportunities, and best practice models.

Increase awareness and support

Financial institutions, government agencies, and others integral to the creation of housing must be led to understand the extent of the housing crisis and be inspired to an increased commitment towards effective and scalable supportive housing. Individuals with developmental disabilities must not be excluded from the affordable housing discussion.

Facilitate inter-ministry collaborations

Addressing the housing needs of individuals with ASD does not fit entirely within the domain of the Ministry of Municipal Affairs and Housing. Inter-ministry collaborations such as those undertaken by the Ministry to target specific disadvantaged populations are needed. These ensure that “housing” means more than just a place to live, but includes the appropriate supports to allow individuals with ASD to thrive and grow, keeping in mind that the degree of support required will vary widely from individual to individual. These collaborations need to include both housing and service agencies at the local, provincial, and federal level.

Conclusion

Individuals with ASD need affordable and supportive housing. Given the wide range of needs and capabilities of individuals on the autism spectrum, creative, innovative, and collaborative approaches to housing are necessary. Developing an appropriate affordable housing program recognizes the value such individuals bring to the community, and provides them the opportunity to live, not just exist.

Appendix

Contributors to this Submission

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

Input for this paper came from: Lynda Beedham, Bonnie Dinning, Jordan Edwards, Susan Fragiadakis, Patricia Gallin, Nelson Lui, Kirk McMahon, Marge McCabe, Laurie Pearce, Todd Smkover, Margaret Spoelstra, Kevin Stoddart.

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

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, parent
- Gerry Bloomfield, Ontario Adult Autism Research & Support Network
- Nancy Cherry, parent
- Eileen Cole, family member
- Dr. Janette Holden, ASD researcher
- Rick Ludkin, Woodview Manor
- Susan Fragiadakis, Geneva Centre for Autism
- Dale Munro, Regional Support Associates
- Staff, Aspergers Society of Ontario
- Glenn Rampton, Kerry's Place
- Doug Reynolds, parent
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- Dr. Kevin Stoddart, ASD Clinician
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