

Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders:

Accessing and Finding Services and Support

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This article summarizes some of the information contained in the report entitled: *"Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems"*.

Information regarding effective and necessary services and supports for the broad spectrum of youth and adults with ASD is lacking (Piven & Rabbin, 2011; Shattuck et al., 2012; Stoddart et al., 2013). Development of this knowledge base requires recognition of the diverse presentations of ASD and an understanding of their complex *bio-psycho-social* needs in a variety of areas including: living arrangements and residential care; recreational and social activities; physical and mental health; employment; and transition services. Ultimately, research is required to inform policy and create a unified, integrated system of care that speaks to the diverse needs of youth and adults with ASD, their families and communities.

Findings from our recent Ontario study of 480 youth (16 years and older) and adults with ASD, family members, and professionals (Stoddart et al., 2013) revealed that respondents were frustrated with uncoordinated, inaccessible, and insufficient ASD services and supports. They also indicated that few professionals were knowledgeable about working with youth and adults with ASD.

Caregiver concerns regarding staff training were also reported in a study by Krauss, Seltzer, and Jacobson (2005). Likewise, Bruder and colleagues (2012) surveyed primary care physicians and found that the majority of physicians felt they had insufficient training to care for their adult patients with ASD; both physicians who had adult patients with ASD as well as those who did not have patients with ASD expressed the need for further training. Overall, capacity building across service sectors is needed to promote ASD awareness,

understanding, and skills among a variety of professionals.

The service provision needs of youth and adults with ASD permeate all facets of adult life and do not only relate to their core ASD characteristics, but also to multiple co-existing challenges. This continuum of services includes residential supports (Krauss et al., 2005), employment opportunities (Hendricks, 2010), socialization experiences (Graetz, 2010), health care needs (Lunsky, Gracey, & Bradley, 2009), transition support (Stoddart et al., 2013), and advocacy training (Clark et al., 2004; Feldman et al., 2012). A survey of caregivers' perceived opportunities for their family members with ASD indicated needs in the areas of socialization, employment, and residential living (Graetz, 2010). According to the same study, the greatest caregiver needs were in the areas of lifelong planning and for additional services. Dissatisfaction with adult services was expressed by a majority of the participants – particularly those caregivers whose family members were more severely affected by ASD (Graetz, 2010).

Not only is it important to consider how individuals with ASD can be integrated into the existing systems, but also the ways in which society can be sensitive to the needs of individuals with ASD and accommodate them (Newsom, Weitlauf, Taylor, & Warren, 2012). Provision of stable funding is an important component in delivering successful ASD services throughout an individual's lifespan (Bryson & Autism Society Ontario, 1991). Furthermore, the integration of funding and service provision must be tailored to the unique needs and strengths of each individual with ASD (Newsom et al., 2012).

Challenges to Developing and Accessing Effective and Relevant Services and Supports:

- Lack of stable funding for individuals and families which may increase financial and emotional stress upon the family
- Uncertainty around funding for service providers may result in lack of consistent, high-quality programs
- Inadequate integration between service providers and institutions across different domains (e.g., educational services, mental health services, developmental services, employment services, health services)
- Insufficient data on the service use and needs of youth and adults with ASD in Canada and the effectiveness of programs to support these individuals

Recommendations for the Community:

- Promote and fund integrated approaches to service delivery to improve cross-system service coordination and program implementation. Examples of services that could be integrated include: social skills intervention; employment support; psychological and pharmacological intervention; behavioural support; residential services.
- Develop funding mechanisms that encourage program evaluation and increase data collection on the services and supports use and needs. Organizations that offer evidence-based services will continue to do so, and those that do not, will be encouraged to evaluate their services and take measured steps towards improvement.
- Develop standards and guidelines for youth and adult service providers so that they have clear benchmarks on how to deliver quality services.
- Increase ongoing collaboration between training institutions (e.g., colleges and universities) and current service providers through internships, cooperative learning programs, and collaborative projects. As a result, young professionals entering the field of ASD will have the current knowledge and skills essential to work with this unique population. Likewise, service providers already in the field of ASD will remain current regarding new research and effective interventions.

- Encourage cross-discipline knowledge exchange and training to enable professionals from a range of disciplines to increase their understanding of ASD and how to serve their clients with ASD more effectively. For example, cross-discipline information exchange may occur between the following professions: career counsellors at post-secondary institutions; physicians and medical students; adult mental health services providers; social workers; psychologists; occupational therapists
- Explore alternative and complementary methods of in-person service delivery, (including the Internet-based delivery) to increase service accessibility and options, especially to remote areas of the province (e.g., online individual intervention, video conferencing and team consultations). Encourage research and evaluation on the effectiveness of these new methodologies.

Recommendations for the Individual and Family:

- Connect with your local Developmental Service Ontario agency, service providers, and advocacy groups. Avoid isolating yourself or your family member. The encouragement and knowledge sharing that occurs within the local community are powerful tools to obtain support and information about relevant services.
- Embrace a spirit of collaboration with service providers to identify the services and supports that are a priority for you or your family member.
- Provide feedback on the quality of the services and supports that you receive thereby allowing service providers to continue doing what they do well, while simultaneously facilitating improvement in areas of their delivery models/programs requiring further development.
- If you are still in high school, participate in developing your transition plan and consider enrolling in transitional services that focus on life skills training, independent living, and employment support.
- If you are not sure about the quality or the effectiveness of the service(s) or support(s) that you are receiving, talk to your friends, family members,

counsellors, or support workers. Share your concerns and seek their help.

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