

## **Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders:** Medical and Health Issues

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The medical and health issues of older youth and adults on the autism spectrum is an area which has not been adequately addressed in the professional literature. Research about children who have autism spectrum disorders (ASD) suggests some medical conditions (e.g., gastrointestinal complaints) are more prevalent than in the general population. It can be assumed many of these medical conditions continue into adulthood. Similarly, there are health issues that typically present in adulthood in the general population that we would also expect to occur in those on the autism spectrum. However, little has been done to determine the prevalence or severity of health issues in adults with ASD.

Our recent provincial study (Stoddart et al., 2013) surveyed individuals with ASD and their carers about physical health and related issues experienced by those 16 and older. Of 480 respondents, 296 medical conditions were reported then grouped by category. Of these conditions, 92 individuals reported one condition, 48 had two, and 36 reported three. They included disorders of the following systems: brain and spinal cord, digestive, respiratory, immune, liver, kidney and urinary, hormonal and metabolic, and musculoskeletal. Also identified were cardiac disorders, hypertension, vision and hearing impairments, and disorders of skin, sleep and weight. Some of the specific disorders named were epilepsy, headaches, gastroesophageal reflux, irritable bowel syndrome and related disorders, thyroid disorders, diabetes, asthma and allergies, eczema, high blood pressure, high cholesterol, arthritis, scoliosis and fibromyalgia.

With respect to accessing medical service

providers, survey respondents made statements such as: “It is difficult to find medical doctors who will accept patients with ASD”; “last two years multiple health problems that were not properly investigated...underserved area”; “shortage of knowledgeable physicians in the area” (pg. 25). As clinicians, we are sometimes told by adults on the spectrum that their health providers don’t take their medical complaints seriously. In their recent chapter on medical issues in adults with ASD, Burke and Stoddart (2013) quote a client report: “I can’t find a medical doctor who is willing to work with me without the drugs that I get all the side-effects for, unpredictable intended effects, and wild-card effects that don’t show up in the literature at all”.

Individuals on the autism spectrum have “unique neurobiology” (Bradley and Caldwell, 2013). This affects both their perception of and their response to situations. If the impact is true for sensory, movement, emotional, perceptual and other systems of functioning, then why would it not impact their experience of and response to health issues? If it does, this may affect their ability to explain their difficulties in terms that are understood by their health care provider. As a consequence, it may, in some situations, lead to appropriate investigations not being done or inappropriate investigations being done that do not target the underlying cause of the individual’s discomfort.

We know that individuals on the autism spectrum do not always have regular medical appointments. When they do see their health provider, they may have difficulty in communicating their bodily discomforts and experiences. This may be due

to not having adequate language or in using unusual descriptive terms, their reluctance to try to explain due to past negative experience, and not always knowing what is “normal”. These will certainly affect the physician’s ability to understand their physical status and physical discomforts.

It is important that steps be implemented to increase the ability of the individual with ASD to explain their health experiences, and for their physician to better understand what the individual is communicating. As information is increasingly becoming available about health issues that may affect those with ASD, screening individuals for these conditions will be important. A family history of medical conditions should be compiled, if possible, with the assistance of a family member, because the individual may not be aware of health issues in extended family members or understand the relevance of others’ health issues to his or her experience. It will also be important that their discomforts are acknowledged, even if their symptoms or their test results are not typical.

Assistance in explaining their symptoms may be achieved by family or other supportive individuals helping to document their experiences prior to a medical appointment; and for the health care provider to have visual tools to aid communication and understanding, as well as tools to guide autism-specific proactive medical care and surveillance across the lifespan (Bradley et al., in preparation).

### Recommendations for the community:

- Build capacity in the health professions (e.g., medicine, nursing, social work, psychology, occupational therapy) by offering and encouraging attendance at ASD workshops and conferences
- Develop ASD-specific standards of medical care (e.g., practice guidelines) and support (e.g., tools for implementing practices, mentorship programs, professional internships/practica)
- Develop local clinical networks of health specialists with expertise and/or willingness to work with people with ASD
- Share expertise and clinical support through presentations, workshops and online discussions.
- Make available (e.g., online and in primary care provider offices) information re: health matters in

patient-friendly formats (e.g., visual presentation, plain language)

- Carry out research on ASD-specific health issues and vulnerabilities

### Recommendations for the health care provider

- Attend to:
  - office accommodations for patients with ASD (e.g., brief waiting time, reduced office lighting, address sensitivity to touch, etc.)
  - individual communication styles and preferences
  - health vulnerabilities specific to each patient and this patient group as a whole
  - atypical presentation of medical discomforts (e.g., hypo- or hyper-sensitivity)
- Engage in continuous professional development in ASD-related health updates

### Recommendations for the individual and their family:

- Keep health records and have available when needed:
  - Past health assessments, investigations, treatments, hospital admissions
  - Records of past and current medications and response to these
  - Family history of physical illness and response to medications
- Document idiosyncratic response to pain and discomfort and share with health care team
- Find ways to communicate effectively with health care provider while respecting youth/adult need for independence and confidentiality
- Work with health care providers to encourage meaningful participation of the individual with ASD in their health care
- Identify and document needs for ASD-specific health care provider accommodations in the office setting

- Undertake regular health assessments and routine investigations (even if there are no immediate medical concerns)
- Build relationships with local network of health care providers

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