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# LAYING THE FOUNDATION FOR POLICY: MEASURING LOCAL PREVALENCE FOR AUTISM SPECTRUM DISORDER

## WHY IS THIS AN IMPORTANT ISSUE?

Autism Spectrum Disorder (ASD)[1] is the most common neurological condition diagnosed in children in Canada. Estimates of prevalence are reported as national numbers but may not reflect local numbers and consequently local needs. Local and provincial ASD prevalence estimates can be used by policy makers to inform local service delivery, resource allocation and future planning.

## WHAT DOES THE RESEARCH TELL US?

### ASD prevalence is on the rise

Estimates of ASD prevalence in Canada have risen dramatically over the past several decades.[2] The reason for the dramatic rise is uncertain and may be a result of a combination of a true rise in incidence, changing diagnostic criteria and increased awareness.[3] It has been speculated that Alberta may have higher numbers of persons with ASD due to family in-migration to utilize higher levels of funding for ASD supports compared to other provinces.[4] Prior to this study, there were no prevalence estimates for Alberta to assess this theory. A better understanding of Alberta ASD prevalence is critical as these estimates assist policy-makers, clinicians and educators in planning for school supports, adult day programs, employment programs, housing options and other programs essential to enhancing quality of life for individuals living with ASD and their families.[5]

### National level ASD prevalence estimation is costly and may not reflect local needs

Accurate national estimates of ASD prevalence are difficult to acquire, and can be an expensive undertaking.[6] Challenges in obtaining accurate estimates are rooted in the limitations of different surveillance methods, such as the need for appropriate infrastructure, labour, sample sizes and consistent diagnostic criteria.[7] International estimates may not reflect local needs. Researchers question the accuracy of applying national estimates to specific geographical areas.[8]

### School records can be used to estimate local ASD prevalence

The use of school records in this 'school census' study provided a feasible way to measure local prevalence of ASD. School board records constitute a complete and comprehensive one-source dataset within a region as schools generally are universally accessed by all children 5 to 17 years of age, including children with ASD. These types of one-source record reviews (which do not include health records and may not capture all diagnosed) risk producing conservative estimates due to this lack of sensitivity.[9] However, this approach can be a cost effective and informative method of estimating local need.

### 1 in 94 school age children in the Calgary region have an ASD diagnosis

The prevalence of ASD for children across all school boards in grades 1 to 12 is estimated to be 1 in 94 (with a ratio of boys to girls of 5.2:1). This prevalence of 1 in 94 reflects national estimates for Canada[10] and does not indicate that Alberta experiences higher numbers of ASD due to in-migration for services. However, this overall prevalence is significantly different than the prevalence quoted by the CDC of 1 in 68.[11] Results from this Alberta-based prevalence study[12] provide guidance for policy makers in Alberta by utilizing data from school records for Calgary and surrounding school boards. For example, 89 per cent of children with ASD were considered severe in an educational setting, suggesting higher levels of support are needed for those with ASD and their caregivers.[13]

### 1 in 86 children with ASD are diagnosed in in elementary grades alone

When the records are grouped by grades (grades 1 to 6), the number of children diagnosed in elementary school was 1 in 86.[14] This indicates a significantly higher number of children with ASD in elementary grades, but these findings were specific to one school board. The reasons for this rise are unknown, but may reflect a combination of the following: A true rise in prevalence for younger children with ASD over the past decade (a possibility noted by Canadian researchers),[15] students in senior grades dropping out of school or moving to home schooling situations (not captured in this study), and/or improved diagnostic screening, changing diagnostic criteria or general increased awareness of ASD.[16]

## WHAT ARE THE NEXT STEPS?

Prevalence estimation has an important role in informing policy on local issues and resource allocation. With rising ASD prevalence, there is added urgency to government policy discussions. These types of estimates are critical for managing the needs of the ASD population across the lifespan, informing policy and planning for the costs required to support students, and streamlining resources required for school supports, adult services, employment programs and housing options. The complete report on prevalence can be accessed at http://www.policyschool.ca/wp-content/uploads/2014/09/Autism-Prevalence-Lowe-Dudley-Dutton-Zwicker-McMorris-Emery-Nicholas-Clarke.pdf.

Three key recommendations based on this prevalence study include:

1.  **Provincial government could consider using school records to monitor local numbers**
    School records can be used to provide estimates that reflect geographic areas for high-prevalence childhood conditions such as ASD and other conditions, like ADHD. School records provide important information to policy makers and represent a feasible and pragmatic approach to surveillance. This school based administrative coding approach offers an opportunity to conduct ongoing surveillance, monitoring changes in prevalence over the school years, and supporting better planning and resourcing of school-based supports. As these data are important for provincial Education, Human Services and Health departments, we recommend these three ministries share the cost of adding this budget line item to existing school board budgets.

2.  **Use school records to track future needs beyond Grade 12**
    Information about persons with ASD transitioning from school to adulthood is needed to inform policy with a lifespan perspective. School records can help capture information on post-secondary education, employment, living arrangements and other outcomes to inform service needs. This information can be used to evaluate current or piloted approaches to inform changes in resources, programs and other interventions for children and adolescents with ASD. Ultimately, this data could highlight issues that exist during transition, also referred to as the "support cliff", when adolescents age into a less systematized, less generous support systems available for adults with neurodevelopmental disability.

3.  **Collect information on the mental health needs of those with ASD**
    ASD typically presents with psychiatric co-morbidities, which adds to the heterogeneity of needs for supports amongst the ASD student population. Including information on psychiatric co-morbidities in surveillance is a step towards tailoring multidisciplinary supports to meet mental health needs and improve quality of life for persons with ASD.

## Notes

1. Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition marked by impaired social interaction, repetitive behaviours, restricted interests and impaired communication.

2. E. Fombonne, "Epidemiological surveys of autism and other pervasive developmental disorders: An update," *Journal of Autism and Developmental Disorders* 33 (2003): 365-82; E. Fombonne, "The changing epidemiology of autism," *Journal of Applied Research in Intellectual Disabilities* 18 (2005): 281-294; J. Pinborough-Zimmerman et al., "Changes in the administrative prevalence of autism spectrum disorders: contributions of special education and health from 2002-2008," *Journal of Autism and Developmental Disorders* 42 (2012): 521-530. H. Ouellette-Kuntz et al., "The changing prevalence of autism in three regions of Canada," *Journal of Autism and Developmental Disorders* 44 (2014): 120-136.

3. G. Russell, "The rise and rise of the autism diagnosis," *Autism* 2, 1 (2012): 1000e104.

4. Library of Parliament, "Provincial and territorial funding programs for autism therapy" (Parliamentary Information and Research Service: 2006).

5. C.J. Newschaffer and L.K. Curran, 'Autism: an emerging public health problem," *Public Health Reports* 118, 5 (2003): 393-399.

6. H. Ouellette-Kuntz et al., "National epidemiologic database for the study of autism in Canada (NEDSAC)," *Chronic Diseases and Injuries in Canada* 32, 2 (2012): 84-89.

7. The methods include: clinical screening and comprehensive clinical evaluation; surveys; service registries and administrative databases; and multi-record reviews of health and education records. R. Nonkin Avchen et al. 'Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders," *Journal of Autism and Developmental Disorders* 41 (2011): 227-236.

8. D.Mandell and L. Lecavalier,"Should we believe the Centers for Disease Control and Prevention's Autism Spectrum Disorder estimates?" *Autism* 18, 5 (2014): 482-484.

9. Nonkin Avchen et al. "Evaulation."

10. Autism Ontario: What is the best estimate of prevalence of autism in Canada? http://autismontario. novosolutions.net/default.asp?id=133.

11. CDC, "Prevalence" (2012).

12. Lowe, Dudley, Dutton, Zwicker, McMorris, Emery, Nicholas and Clarke. Laying the Foundation for policy: Measuring local prevalence for autism spectrum disorder. The School of Public Policy, University of Calgary. *SPP Research Papers*, Vol. 7 (28), September 2014.

13. Brown et al., "Beyond."

14. Lowe, Dudley, Dutton, Zwicker, McMorris, Emery, Nicholas and Clarke. Laying the Foundation for policy: Measuring local prevalence for autism spectrum disorder. The School of Public Policy, University of Calgary. *SPP Research Papers*, Vol. 7 (28), September 2014.

15. H. Ouellette-Kuntz et al., "The changing prevalence of autism in three regions of Canada," *Journal of Autism and Developmental Disorders* 44 (2014): 120-136.

16. J.L. Matson and A.M. Kozlowski, "The increasing prevalence of autism spectrum disorders," *Research in Autism Spectrum Disorders* 5 (2011): 418-425.