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## MIND THE GAP: TRANSPORTATION CHALLENGES FOR INDIVIDUALS LIVING WITH AUTISM SPECTRUM DISORDER

### WHY IS THIS AN IMPORTANT ISSUE?

An estimated 1 in 86 children are diagnosed with Autism Spectrum Disorder (ASD)<sup>1</sup> making it the most commonly diagnosed childhood neurological condition in Canada.<sup>2</sup> Transportation challenges for those with ASD are a growing issue in Canada. People living with ASD<sup>3</sup> and others who live with neurodevelopmental disability (NDD)<sup>4</sup> rely almost exclusively on public transit and caregivers for transportation. The current transportation options are insufficient in meeting the needs of this population.

### WHAT DOES THE RESEARCH TELL US?

#### Transportation is essential to promoting quality of life

The transit system plays an essential role in improving quality of life for individuals with ASD and for their caregivers. However, problems with cognition, perception and communication are barriers to independence in transportation. Availability of transportation is critical to enable high levels of physical activity among those with intellectual disabilities.<sup>5</sup> Safe and reliable transportation improves one's ability to participate in programs that support quality of life and impacts employment, volunteering, religious participation, exercise, self-advocacy and health care for people with intellectual and developmental disabilities.<sup>6</sup> Caregivers for those with ASD emphasize that transportation is critical to enable meaningful opportunity and community engagement in employment, education, healthcare and social pursuits.<sup>7</sup>

## **Transportation policy and programming is not meeting ASD needs**

Very few individuals with ASD are able to drive and many struggle using public transportation; leaving them to rely on family and friends to meet their transportation needs.<sup>8,9</sup> An environmental scan of transportation policy of four provinces<sup>10</sup> revealed that little existed to address the needs of those with NDD. Key transportation challenges for this population include: difficulty on the public transit system comprehending directions and planning trips, difficulty crossing roads safely when walking, a lack of information about services, no regular services, lack of safety regulations on special need buses, unreliable and inflexible special needs transport and taxis being too expensive.<sup>11, 12, 13, 14</sup> The National Council on Disabilities in the United States identified underfunding and lack of flexibility of paratransit as barriers to transportation for the cognitively impaired.<sup>15</sup> As a result the majority of the ASD population (80 per cent) are highly reliant on family and friends to meet their transportation needs<sup>16</sup> and 72 per cent of parents and caregivers say they miss their own activities, take low-paying jobs or give up employment in order to drive their children and adults with ASD.<sup>17</sup> Lack of safe reliable transportation and the resulting loss of employment income contribute to overall costs of autism.<sup>18, 19</sup>

## **A gap in Canadian ASD transportation research, policy and programming**

Transport policies and programs designed for persons with these challenges in mind are needed. The commitment to ensure access for all people living with a disability is well documented<sup>20</sup> and progress can be seen for those living with physical disability and seniors (such as parking placards, motor vehicle modifications, better street lighting, wheel chair access and transit training programs).<sup>21</sup> However, reports throughout North America find that the transportation system has many barriers to access,<sup>22, 23</sup> in particular for persons living with ASD.<sup>24</sup> Key areas to be addressed include:

- Developing a transit system with cohesive and consistent service delivery. Currently a patchwork of services, availability, quality and access exists between municipalities and across provinces.<sup>25</sup> The complexity of the transit system, the lack of standards and municipal delivery result in unregulated, fragmented and variable services.
- Funding programs for those with ASD rarely mention the need for safe, efficient and reliable transportation. One promising example from Ontario (The Passport Program) has funding for adults with developmental disability to develop skills in utilizing transportation services.
- Transit upgrades for disability should include those with neurodevelopmental disability. Currently upgrades are designed to meet seniors' needs or persons with physical disability or sensory needs (vision/hearing impairment).<sup>26</sup> However, there is promising research on information technology (IT) for individuals with cognitive disability and brain injury that may enhance independence for people with ASD who are capable of managing IT systems.<sup>27</sup> The International Transport Forum (2009)<sup>28</sup> for cognitive and mental health transport identifies good practice ideas across European countries like: the presence of staff at interchanges, real-time audio on all transit including buses, physical design features that include pictures and thoughtful layout of facilities. Incorporation of new research and innovative best practices in these areas is needed.

## WHAT ARE THE NEXT STEPS?

Local and provincial governments need to be more involved in the delivery and standards of transportation for those with neurodevelopmental conditions, like ASD, and other vulnerable populations. Improved access will improve health, well-being and financial independence and relieve caregivers of constant transport duties allowing them time to maintain employment and lessen stress. Some key recommendations for improvement include the need for consultation, funding and research. The complete transportation report and full recommendations can be accessed at <https://www.theabilityhub.org/resources/books-and-publications>.

- 1. Consult with persons living with ASD and families.** The voices of those with ASD (both high and low functioning) and their families need to be represented in the decision making process for municipal transit initiatives. Transit improvements need to respond to the needs of those with ASD and other disabilities, and this can only be done by working collaboratively with those using the services. This consultation process needs to recognize the significant impact transportation has on family burden and individual well-being.
- 2. Ensure adequate funding for safe, efficient and reliable service.** Funding initiatives are needed for: increased public awareness and driver training, adequate levels of service for children and adults on special needs busing, programs where funds can be used to support training to enhance independence on transportation (like those of the Ontario Passport program) and enhanced municipal transit-run training programs.
- 3. Support further research.** Increase the understanding of how individuals with ASD in Canada are getting around, what the problems are and how to improve independence, safety and efficiency. Examples such as IT strategies<sup>29</sup> to improve independence of individuals with ASD on fixed routes are promising and warrant more research for optimal implementation.

## Notes

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