

Discussion Panel on Residential Options for Those on the Autism Spectrum

June 2018

Summary Report



Executive Summary

What happens when our loved ones grow up? What happens when we can no longer care for them ourselves? What are the unique factors that need to be considered when trying to provide the right 'fit' for those on the spectrum?

On May 2, 2018, the Autism Society, Newfoundland & Labrador, hosted a panel to begin a conversation about residential options for the unique realities challenging those on the spectrum face when searching for a suitable place to live. People with ASD vary in their need for supports related to housing and adult living. Some can live independently; others require assistance with daily living tasks; some may need intensive, 24-hour supportive care.

Government has committed to the release of a comprehensive *Autism Action Plan* in Fall 2018 (Way Forward: **Action 3.11.3 Providing Better Services to Persons Living with and Treating Autism**) that will include:

- Development and implementation a new 'whole-of-government' approach to treating autism that ensures more integrated autism-related services for children and adults;
- Exploration of clinical assessment models that support better allocation of resources,
- More informed decision-making regarding eligibility for services and support.

Currently, most funding, research and resources are allocated to programming and services for younger individuals on the spectrum. This includes improvements to early assessment, early intervention/ therapy, and in-school supports. While the increase in supports and services for children and youth is fabulous, we cannot forget that older individuals on the spectrum need support too. This situation becomes even more critical for those whose parents have aged, and/or passed away, leaving these individuals without their primary and sole source of financial, emotional, housing and life support. With an aging population, now is the time to act.

Canada's census data from 2016 indicates that, for the very first time, seniors outnumber children in Canada. The median age of the Canadian population is 41.2, six months older than the median age 5 years prior. Further complicating this situation in the autism community are recent statistics released by the Public Health Agency of Canada, indicating that 1 in 66 youth, ages 5- 17 years, have an autism spectrum disorder diagnosis. The prevalence in Newfoundland & Labrador is 1 in 57, the highest prevalence rate among provinces participating in the National Autism Surveillance System (NASS) to date. These children have caregivers/parents who are aging. Any policy decisions taken as part of an Autism Action Plan must have the foresight to ensure parents and their aging children on the spectrum are supported through the transition to adulthood.

The May 2, 2018 discussion highlighted two key opportunities to reduce strain families are facing as they look to a future that requires residential supports for their loved ones. First, increased training and education for professionals working with families and individuals in the system will have a significant impact. Second, beginning transition planning to adulthood in the early years and onwards is a significant step towards setting adults up for a healthier, happier, more fulfilling adulthood.

When evaluating specific housing options, a comprehensive jurisdictional scan of existing housing and residential options in areas outside Newfoundland & Labrador is needed to ensure that, moving forward, decisions consider successes and failures in other areas.

These conversations are occurring at an opportune time. Canada is moving forward with a ten-year National Housing Strategy, and the Newfoundland & Labrador Provincial Government is formulating an Autism Action Plan. Discussions such as that at the recent panel are needed as the Provincial Government reviews programming and services for those with complex needs; as the Newfoundland & Labrador Housing Corporation continues to develop a new and comprehensive provincial housing and homelessness plan; and as the Province participates in a multilateral Housing Partnership Framework with other Provinces and Territories.

This document summarizes major discussion points from the panel, recommendations for the Autism Action Plan, and a snapshot of who the panel reached and feedback given to ASNL.

Theme 1.0 – Training and Education

Each of the panelists, as well as audience members and feedback survey respondents, indicated that training and education of service providers is a huge opportunity for improved service delivery. Comments included:

- The system is not ready for the aging adults
- Very few workers (social workers, educators, doctors, nurses, community health etc.) are aware of the unique aspects of ASD or have training in ASD.
- A lot of education needs to be provided to professionals in the field
- ASNL educated Eastern Health social workers about autism and a client's unique needs as a person with ASD
- There is a need for home/residential options, but there is also a need for trained professionals attached to them
- Individuals with the most complex needs are being forgotten by the system
- We need comprehensive training, at regular intervals – for all healthcare, education, community workers and social workers
- There is a deficit of professional knowledge about autism in all service sectors
- Physicians need to have a better understanding of ASD
- More education about autism is needed, especially for teachers

ASNL recognizes increased training and education for professionals in the field is needed for many specific health conditions. The following recommendations are being put forward because training and early identification of ASD can change the trajectory of an individual's life entirely.

Recommendation 1.1: In-Service Education/Training for Healthcare Workers in Regional Health Authorities

The Autism Action Plan must include a strategy for basic in-service education/training for all those who may be included in the “circle of care” for an individual on the spectrum, including physicians, nurses, social workers, psychologists, and allied health professionals. This education should be mandatory for all Regional Health Authority staff.

Recommendation 1.2: Professional Development Opportunities for Physicians

To address the knowledge gap families have experienced with family physicians, the current Medical School Curriculum should be evaluated to ensure ASD is included. Increasing prevalence requires a better understanding by physicians, not simply for early detection but rather the purpose of effective intervention and treatment throughout the life span. The curriculum should also be evaluated to see where ASD may be included when learning other topics (i.e. communication strategies that may work for some dementia patients may also be effective for some individuals on the autism spectrum).

Recommendation 1.3: Development of Online Modules Related to ASD and Mental Health

The online professional development series for educators (APSEA) has been effective in reaching nearly 1000 educators. ASNL still recommends a similar online series that provides a basic understanding of ASD be utilized for mental health professionals.

Theme 2.0 – The Importance of Transition Planning

Families are struggling with the transition of their loved ones from younger years into adulthood. During the panel discussion, comments were made related to transitioning, difficulties with navigating supports and the need for more life skills planning/programming for people on the spectrum. Comments included:

- It is preparing in advance that is so important to transitioning
- Concrete supports are needed; financial planning, cleaning/hygiene skills, cooking, grocery shopping, how to use public transportation.
- Basic life skills need to be taught early
- Structure/routine are helpful; less structure with adolescence sees issues escalating
- Ways to access services must be streamlined; information needs to be centralized.
- We know what students need to know when leaving K-12; we must help them get ready
- A family-centred approach to transition planning is needed
- Plans based on Individualized needs must become a reality. The continuum of supports is important to a successful transition. The plan needs to be updated and grow with an individual throughout schooling and into adulthood.
- Paid, dedicated ‘navigators’ are needed
- Information is needed on options/services difficult to access and navigate, especially for aging parents; caregivers are already exhausted by care.

Recommendation 2.1: Implementation of a Provincial Autism Services Office

Families and people on the spectrum need assistance with navigating the system of supports and services. Rather than having to seek out the information they need from multiple departments, an Autism Services Office can connect people to these services/supports. This is particularly critical for those who receive a late diagnosis. For those who enter the ‘system’ during pediatric years, there are several entry points: through diagnosis, early intervention, therapy and even the education system. For an adult seeking a diagnosis and support, it is unclear where to begin or who to call.

Recommendation 2.2: Mandatory Transition Planning and Documentation

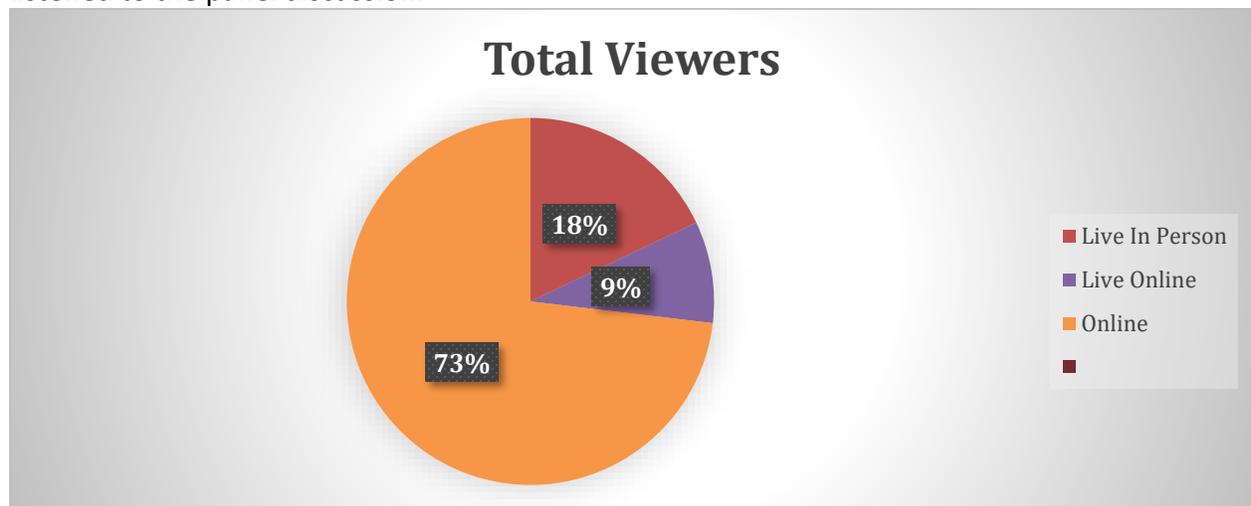
Policies requiring regular team meetings (circle of care) and transition planning may exist on paper, but if they are not being followed, or if professionals choose to ignore them, individuals on the spectrum and their families are being mistreated; quality of life is not reaching its potential. Strict requirements around following policy directives and providing documentation are required. Furthermore, when the person(s) in charge fails to meet obligations that flow from the policy and regulations, accountability measures must be in place and enforced.

Recommendation 2.3: Pilot a Life Skills Program

Implement a life skills program across the province, connecting individuals of all abilities to skill development programming to increase independence and well-being. This programming will be available for any individual with complex needs, not just those on the spectrum. Programming will be made available to accommodate a diverse set of abilities and it will be accessible to all learning styles. Topics will include hygiene, banking/finance, shopping, cooking, etc.

Who Attended/Listened

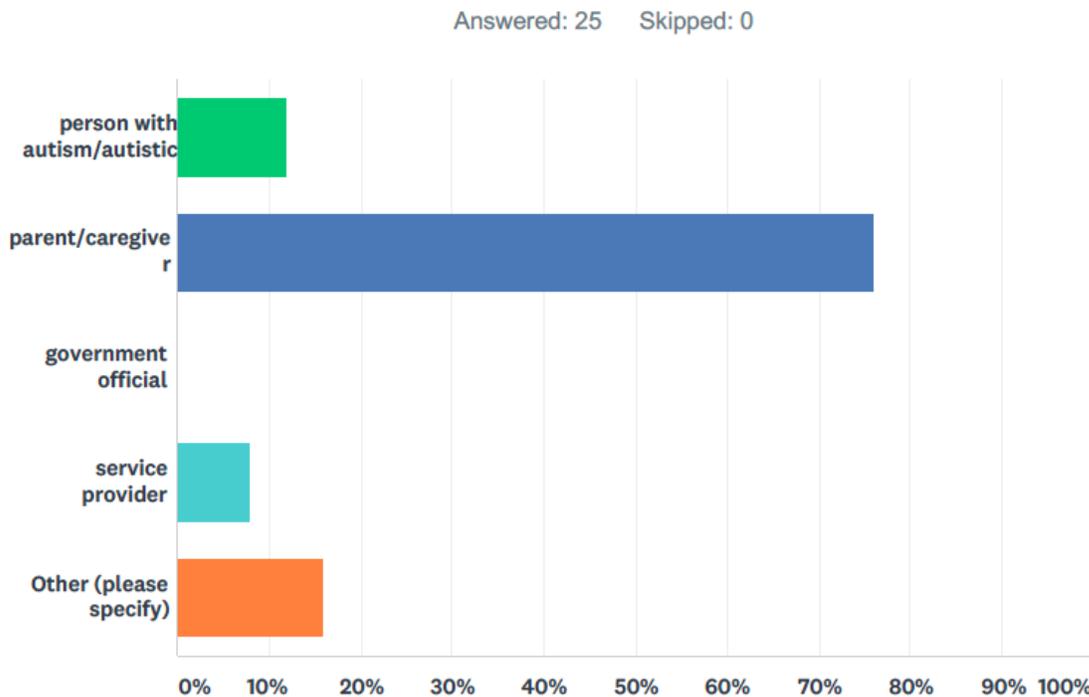
This panel was the first large-scale event where ASNL livestreamed online to expand reach, during and after the panel. Sixty-four (64) people attended and participated at the Suncor Energy Hall. During the event, ASNL reached another 32 viewers online. By the end of May 2, 2018, the panel stream had been viewed a total of 136 times (Canada: 134; United Kingdom: 1; Japan: 1). Since the live event, the total number of views online is 261. In total, 357 people have listened to the panel discussion.



Feedback Survey Data

Following the panel discussion, on May 4th, 2018, an online feedback survey was distributed to those who had registered to attend in-person or online. With 25 respondents, the sample size is just 7% of those who participated. However, it does provide a snapshot of the experience/demographic of those who attended in-person or listened/watched online. Not surprisingly, the majority of those who responded were parents/caregivers. The second highest response was from adults on the spectrum (3 reported directly they were on the spectrum; 2 others who identified themselves as having autism replied 'other'). A summary of responses can be seen in the figure below.

Q1 Which of the following describes you?



Conclusion

The May 2, 2018 panel discussion provided an opportunity for ASNL to connect with the community on an issue that is concerning for many families. For aging parents, the future is daunting. The Autism Action Plan must take steps to ensure those on the spectrum who are exiting the pediatric system do not 'fall into the cracks'. The discussion highlighted opportunities for service improvements that would put families on the right track from the early years into adulthood. First, professional development and training is required for all service providers. Second, transition planning needs to become a reality, with improved service navigation, a focus on life skills development and mandatory transition plans that adapt to an individual's needs over time. There was a time when service provision could not meet the needs because of a lack of awareness of ASD; that time has passed. The prevalence of ASD in Newfoundland & Labrador, and the constant public attention to the lack of adequate services,

demand the system “catch up”. Autism Society, Newfoundland & Labrador, will continue to push for improved services and supports for those on the spectrum and their families.

References

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