



Building to Better: A White Paper on Supported Housing for the Autism and Developmental Disability Community

EXECUTIVE SUMMARY & RECOMMENDATIONS

Executive Summary

Nova Scotia is moving toward a better system of supports for people with disabilities. In line with jurisdictions worldwide, and inspired by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), the province is transitioning from institutions that isolate people from communities, towards a model of housing and supports focused on increasing active participation in social, economic, and political life. Nova Scotians, including people with Autism and other developmental disabilities, their families, advocates and service providers, have been calling for these changes for decades.

The conversation around supported housing is less about bricks and mortar, and more about the support needs and quality of life indicators that reflect the needs and wants of the individual. These “person-centred” and “person-directed” models or support frameworks are widely understood as essential to building societies that prioritize “choice, dignity, agency, pride, confidence, self-worth, high quality of life, and overall wellbeing”¹ for all people, including those with disabilities.

The options for supported living can vary, from small-options, group homes, live-in support, mixed-purpose apartments with support visits, to apartments attached to family homes with intervals of support, and other flexible arrangements that reflect the needs and choice of the individual. There is an overwhelming demand for more housing options that prioritizes the person, and their quality of life at the centre of decision-making.

The consensus reached by the disability community in the recent Ideas: A Supported Housing Summit, and consultation thereafter, clearly indicates that the process of moving to a more desired, person-directed system is happening too slowly, leaving many Nova Scotians either in a housing crisis or struggling to figure out how to, for themselves or for those they care for, move to supported living options that helps increase autonomy and quality of life.

Embracing and investing in supported community housing

models is an important step, but still only the first toward realizing a better system. As many individuals with Autism and other developmental disabilities have found as they seek housing and related supports, there are challenges and barriers that frustrate efforts to improve living options at the individual and societal levels.

As this White Paper documents:

- Clear **need or demand** for supported housing is poorly understood and difficult to quantify due to current practices that collect this information across the province.
- The **availability** of bricks-and-mortar homes and access to support services, including trained support providers, is **insufficient** to meet even the lowest estimation of demand.
- Individuals on the Autism Spectrum and other developmental disabilities and their **families struggle to access information** about the range of options available, or the sources and combinations of funding to pay for them.
- **Social inequalities among families complicate access** further, with some families using their social and economic capital to navigate complex systems and establish living arrangements, and others utterly lost about how to even begin, or unable to leverage the resources to start.

¹ Ontario Developmental Services Housing Task Force “Final Report 2018. Generating Ideas and Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities.”

These broad challenges are further linked to additional systemic problems, such as **rural-urban inequities** in the availability of housing and support, the important question of how systems and service support individuals with **behaviours that challenge**, and a lack of coordination between sectors of government and society such as, community services, health, social, justice and community-based supports.

The barriers described further in this White Paper are necessary to describe and analyse, because they are real and will affect the next steps of our journey toward a better system. At first glance, they might seem overwhelming, but they are not impossible to overcome. Other jurisdictions are already building these systemic and individualized systems and are leading the way, showing us that it can be done. We just need to listen!

Autism Nova Scotia's consultations with its community, with policymakers, and with system architects from other places, show us that the biggest shift is already happening: the shift away from serving the system to a system that serves and supports people. When new types of support are demanded, the question always becomes: 'can the system afford this?' We believe that there are two better questions: first, 'can the system help the individual afford this?' And second, 'in the long run, can the system afford *not* to do this?' The shift toward these questions is the shift from a system-centred approach to system-facilitated thinking, and it is the shift we need to nurture and embrace as we move forward together as a province.

It is also the approach that informs the recommendations in this White Paper, each of which speaks to one of three overarching recommendations:

First, Nova Scotia needs to work better together. There is an urgent need to align all aspects of its disability supports, including supported housing, to adhere to the UN CRPD principles of rights-based, person-centred and person-directed planning, Quality of Life frameworks, and wraparound supports. This includes developing indicators and measures of accountability and evaluation to inform decision-making and improvements for service providers of all sizes and scales.

Second, the province needs to lead in creating and convening a structure for collaboration and cooperation around supported housing among the various stakeholders in disability supports.

Third, a greater investment and allocation of resources will be needed to actualize recommendations in one and two and to achieve efficiencies:

- to *understand* and make available information related to navigating the existing system and the people in it—from quantifying unmet demand for supported housing and gathering data on desires, needs and expectations in the Autism and developmental disabilities communities.
- to work with community and families and service providers in the efforts to expand the availability of supported housing options, including bricks and mortar and responsive supports across the province.
- To provide families and service providers with better guidance and increase understanding about supported housing options.

This paper endeavours to begin the work of understanding the current system and identifying the major gaps in knowledge. With the input of community consultation across two events in the Spring and Fall of 2019, it identifies significant gaps in awareness, access, and system coordination. Drawing on experiences from other jurisdictions, and literature in this area, this paper offers a first look at "leading and best practices" in supported housing around the world.

Overall, the paper is meant to be a catalyst for future conversations and collaboration, while also offering concrete and achievable recommendations for immediate action. Building to better will take time, but action from all those who make up the supported housing community must start now. It is not the work of one person or group, but the work of many, working together, that will change the system for the better.

Recommendations

Better Understanding the Demand for Supported Housing

1. Good decision making requires a more accurate understanding of the number of people with Autism Spectrum Disorder (ASD), and Developmental Disabilities (DD) as well as the availability of supported housing in each county or region. The Department of Community Services (DCS) should develop a standardized and clear index and measurables to determine the need for supported housing, with which to inform any planning around supported housing in Nova Scotia.

Improving and Building a Solid System for Supported Housing Decision Making:

2. To ensure individuals in health-funded supported care arrangements are connected to person-centred planning, meaningful relationships, and opportunities for broader social inclusion, it is recommended that Department of Health and Wellness/ Nova Scotia Health Authority (DHW/ NSHA) and DCS formalize a structured approach to work more closely and collaboratively as it relates to policies, procedures and resource allocation that may currently present barriers to support in these areas.
3. To ensure that people with ASD/DD are being appropriately assessed for level of support as well as personal, health, and safety goals, it is recommended that the current assessment process be revised to include psychosocial and relationship (QoL) needs to reduce the likelihood of social isolation and other adverse impacts. This should include a Quality of Life Framework that approaches support through an individualized and person-centred lens.
4. Review the current laws, policies, and standards of care used in supported housing arrangements (e.g., Homes for Special Care Act, Adult Capacity Act), and any others that may have a bearing on the effectiveness of person-directed planning and decision making for those with ASD or DD in residential arrangements.

5. DCS re-examine the IQ and other assessment criteria for the DSP programs to ensure that Nova Scotians with ASD and no ID, but whom have support needs, receive the appropriate level of service and supported living options so they can be productive and contributing members in their communities.
6. Many adults struggle with disability related barriers, but lack access to public services to be able to obtain supports that could provide much needed independent or community living options. It is recommended that DHW provide adult diagnostic services for adults who have a suspected but unconfirmed diagnosis of ASD. This service is currently not available in the province of Nova Scotia.
7. Government departments (DCS and DHW as well as Justice) should engage individuals, families, and service providers in collaborative Supported Housing Planning processes, and establish processes or structures that enhance awareness about the sector and options for those working within it.
8. More information must be gathered from the ASD/DD population on issues that consistently create barriers for independence in daily living. This will allow for a greater understanding of the demand and desires of individuals, as well as the number of people who are in supported housing, waiting for supported housing, or not connected to DSP.
9. A centralized waitlist with localized breakdowns of demand and capacity, which accurately reflects the number of people in need of support and the level of supports needed, while also factoring in the persons preferred living arrangement would build a fuller, more reliable, and more actionable understanding of the demand and estimated costs for supported housing.
10. Assign third-party intermediaries such as NGOs/ Community Based Organizations to ensure person-directed plans are articulated and followed, ensuring that DSP for other support funds are connected to the broad purpose of supports beyond the home and social inclusion.

Moving to an Individualized Supports and Housing System

11. A larger investment in innovative supportive housing options and flexible funds with which to realize appropriate and individualized housing arrangements.
12. A clear outline of existing and emerging models, as well as evaluations of those models, should be made available to those exploring options for supportive housing.
13. Create a centralized page that outlines the areas of funding available through DSP, its various streams, as well as other potential sources of funding, and illustrate what areas of a supported housing arrangement those funds could be used for.

Strengthening Supports and Housing to Overcome Barriers

FOR GOVERNMENT

14. A larger investment in innovative supportive housing options that respond to actual demand, and flexible funds with which to realize appropriate and individualized housing arrangements.
15. A working group should establish a framework for moving to a system where individual support dollars help fund supports and housing (distinctly), in which the needs and rights of the person are respected through the creation and regular updating of person-directed plans—over and above support or program plans.
16. DCS must clearly outline what Flex funding is and what types of supports it covers, as relate to housing and daily living. They should also articulate how Flex funding supports the move towards a more individualized structure of funding around housing and supports and make information about the stream and what it covers more publicly available, in clearer language.
17. To build and increase compliance with the development and regular updating of person-directed plans, Government should budget funds for Person-directed Planning development, and, following the lead of other jurisdictions, explore the possibility of making funds for supported housing to any provider contingent on the completion and ongoing updating of a person-directed plan for that individual.

18. Resources are needed to conduct Nova Scotia studies that can help us better understand the specific vulnerabilities of individuals with disabilities to homelessness so that we can understand how to increase access to appropriately supported housing models and strengthen support structures in areas such as mental health.
19. Housing Nova Scotia, or the division of government delegated with its responsibilities, must work more closely with the Disability Support Program to help coordinate the brick and mortar dimensions of supported housing for persons with disabilities, to better meet needs, assure that many of the issues highlighted in this paper are considered, and maximize the benefits of any provincial or national housing strategy, or any other national initiatives to persons with disabilities.

FOR COMMUNITY SECTOR

20. Person-centred plans should be conducted with an individual, and their families or caregivers where appropriate, by a third party. The community sector should work with Government, through programs or other initiatives, to help assure that the disbursement of support dollars and an individual's housing arrangement meets the goals of the individual by offering services that develop and help coordinate the broad social inclusion dimensions of a plan.
21. Funds should be made available to existing service providers, or emerging supports and housing organizations, to conduct evaluations of living and support arrangements. These evaluations should look at the impact of arrangements on individuals and should be made publicly available as “models” to create a foundation of information about models in the province. This would build a much-needed database of models and offer instruction on how they work for those wishing to move towards supported living and housing.
22. Training for staff that can work in a variety of support needs environments, around behavioural supports and person-directed decision making and planning, should be available and developed as a core competency for anyone working in a residential or supported living arrangement. Creation of criteria for residential and supported living core competencies must be accompanied by appropriate funding for professional development.

23. A map or visual guide should be developed for the developmental disability community that outlines the building blocks for moving to a variety of supported housing arrangements, sources of funding in each, and processes for moving to and between each of these sections of the service and supports landscape.

24. A survey should be conducted, following the Massachusetts Model (see larger paper), of individuals and families of persons with disabilities to gain a fuller understanding of the needs and desires of that community, and to gain a sense of the understanding of housing options and pathways to supported homes. Without this type of information, the only data that we have is that gathered through engagement with the DSP, and other disparate system-level data—which fail to give us a first voice and kinship view of what is needed on a lived scale. These findings would help the system anticipate actual demand and expectations.

RECOMMENDATIONS FOR OUR SOCIETY

25. A working group made up of service providers, community based organizations, selfadvocates, families that works closely with an inter-ministerial working group, should convene to establish how to appropriately strengthen agencies or develop new service agencies that can provide operational and administrative supports, for an overhead fee, to the boards of emergent small option homes and independent living arrangements— providing specific services around person-centred planning, staffing, scheduling, training, and payroll of small options which could be equally used in non-congregated housing settings (see the recent outcome report from the Ontario Developmental Services Housing Task Force for more on this.)

26. Existing service providers and government leaders should explore the creation of “batching” or “broker” services, that could aid existing and new housing providers in staffing and training for supports, as well as their operations where appropriate. Such a service would play an important role in broadening scattered and congregate supported housing options, while also acting as a steward of person-directed decision making and monitoring quality of life indicators.

27. A guide to supported housing for individuals and families should be built, customized to the Nova Scotia context, and made available at government, residential, social and health services, and community-based sites, where conversations about supported housing may occur. Additionally, an interactive website or “reader” should be created and built using universal design principles, so that any individual and their families can easily look at options for supported housing, and see what funding (and conditions associated with that funding) may be applicable to that model and their situation.

28. Crisis stabilization tools and tactics must be addressed through a collaborative approach that brings DCS, Health, residential service providers, and community-based organizations together. They should jointly determine what facilities, protocols, and in-home support structures must be implemented to assure that individuals in crisis or immediate need are transitioned, from intense stabilization-care to a proper home, as soon as safely possible.

29. A broader availability and accessibility of wraparound services comprised of practitioners from the Departments of Community Services, Health and Wellness, and/or Justice would create conditions where it was possible for individuals and those in their support circles to identify areas of need and supports, working with the person to address issues early and respond appropriately when a crisis is looming.