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

Pre-Summit Draft

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autism
NOVA SCOTIA

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A note on language: autistics versus persons with autism

It is important to note that although this paper examines support and housing through the lens of ASD and developmental disability (DD), the recommendations that follow are not unique to people with ASD/DD. They apply to all Nova Scotians. Like the recent work being done in other places on supported housing and supportive living, the recommendations are driven by a vision of citizenship for all people with disabilities. We have adopted the standard that switches between "person with autism" and "autistic" identifier, to reflect the diversity of individuals' self-identification in the community.

Please see Appendix A for definitions of common terms used throughout this paper.

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Table of Contents

Acronyms

ASD	Autism Spectrum Disorder
AFSP	Alternative Family Support Program
ARC	Adult Residential Centre
CASDA	Canadian Autism Spectrum Disorder Alliance
CRPD	(United Nations) Convention on the Rights of Persons with Disabilities
CSD	Canadian Survey on Disability
DCS	(Nova Scotia) Department of Community Services
DD	Developmental Disability
DFS	Direct Family Support
DHW	(Nova Scotia) Department of Health and Wellness
DSM 5	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
DSP	Disability Support Program (A Division of the Nova Scotia Department of Community Services)
DRRAP	Disabled Residential Rehabilitation Assistance Program
ESIA	Employment Support Income Assistance
ID	Intellectual Disability
ILS	Independent Living Support
IWK	Isaak Walton Killam Health Centre
ND	Neurodevelopmental Disorders
NS	Nova Scotia
NSHA	Nova Scotia Health Authority
NT	Neurotypical
QOL	Quality of Life
PBS	Positive Behaviour Support
PHAC	Public Health Agency of Canada
RRC	Regional Rehabilitation Centre
SES	Socio-Economic Status
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

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 well-being"[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.

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.

The Task Before Us: Building to Better

In Nova Scotia and across Canada, people with ASD and their families say that their primary concern and unmet need is good housing, with the right supports, in communities that welcome them.[1] Pressure is mounting on the province, like many jurisdictions, to move fully away from institutionalized housing for people with disabilities towards person-directed, community living. But there are inadequacies in the supply of supported housing, a lack of individualized and appropriate supports, and limited access to training for support staff. Identifying these issues in its 2016 *Choosing Now* Report, Autism Nova Scotia urged governments to work with Nova Scotians to increase housing opportunities for people with Autism, eliminate waitlists, and abolish the high number of institutionalized living arrangements. Overall, *Choosing Now* advocated, on the basis of consultations with the autism community, for a dramatic shift in Nova Scotia toward a supported housing system that puts individuals at the center of planning and decision making.

Choosing Now was not the first initiative to foreground housing needs and urge for person-centred planning in Nova Scotia. From the globally influential 2006 UN CRPD (Convention on the Rights of Persons with Disabilities), to the Department of Community Services' 2013 Services for Persons with Disabilities Roadmap Report,[2] there has been a growing "rights-based" call for supported housing in the province. Yet little about the Nova Scotia disability housing landscape reflects the UN CRPD principles and very few if any of the supported housing recommendations from the Roadmap have been put into practice.[3] **Nova Scotians are still wondering what a sustainable, rights-based, person-centred supported housing system looks like, and moreover--how does our province get there? This is not an easy question. It entails asking, further, how can a person-centred supported housing system be *sustained*; how can it ensure that it creates places where people feel they belong, are able to direct their own support to the fullest extent possible, and have a good quality of life?**

In late 2018, building on the insights of the *Roadmap* and *Choosing Now*, Autism Nova Scotia endeavoured to tackle these difficult questions through a more in-depth examination of housing and best practices for our community. The paper, *On the Autism Spectrum in Nova Scotia: Reviewing the Evidence for Supported Housing Models,* dug into the evidence-based best

[1] AMAT, 9; CASDA , National Needs Assessment, 23-27

[2] Choice, Equality and Good Lives in Inclusive Communities. A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program. 2013

[3] Community Homes Action Group (2015, 2017). Report Card on the Progress of the Nova Scotia Government's Transformation of Services for People with Developmental Disabilities.

practices in supported housing and related initiatives, with an emphasis on "person-centred (and directed) planning" and "wraparound" supports. The paper found:

- A "quality of life (QoL)" framework, developed by the World Health Organization and the UN CRPD, is emerging as a beacon directing the development and innovation of supported housing.[4] Indeed, the best practices in supported housing across the world do not start with bricks-and-mortar, with spaces or beds, or even with the very important discussion about a person's medical and behavioural support needs.[5] Rather, at its best, supported housing starts with person-directed planning, in a much larger discussion with the person about how they can live a high-quality life of inclusion in their community.
- Person-Centred Planning and focusing on Quality of Life are not just nice things to do; they are essential and beneficial for societies. Approaches guided by QoL and Person-centred planning principles actually create the most *efficient, effective, and equitable* supported housing system, because it is more navigable and sustainable, and avoids the significant costs associated with pushing off or deferring expenses.[6]
- Realizing the many individual-, community- and system-level benefits of a person-centred supported housing system require a shift in how we think about and operate within the current service system. There is a need to move from a mentality of scarcity, crisis, and "wait-lists" toward an aspirational mentality, focused on the achievement of a person-centered or directed model.[7]

Moving QoL, and person-centred support practices to the forefront of a supported housing system, and becoming more in line with the UN CRPD in so doing, means that any discussion or decisions about housing for persons with disabilities must include with consideration of the following—in order of priority:

- Goals, values and aspirations of the individual
- Social and familial relationships and circles of support (and their alignment with the individual's wishes)[8]
- Availability and affordability of support resources
- Supply of skilled and trained support service providers
- Availability and affordability of housing
- Policies that govern and set compliance standards in the supported housing sector

[4] On the Autism Spectrum, 9.
[5] Kendrick MJ. *An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System*.; 2001.
[6] Buescher AVS, Cidav Z, Knapp M, Mandell DS. Costs of Autism Spectrum Disorders in the United Kingdom and the United States. JAMA Pediatr. 2014;168(8):721; Lunsky Y, Weiss JA, Paquette-Smith M, et al. Predictors of emergency department use by adolescents and adults with autism spectrum disorder: a prospective cohort study. BMJ Open. 2017;7(7); Howlin P, Magiati I. Autism spectrum disorder: Outcomes in adulthood. Curr Opin Psychiatry. 2017;30(2):69-76; Anderson K, Roux A, Kuo A, Shattuck P. Social-ecological Correlates in Adult Autism Outcome Studies: A scoping review. Pediatrics. 2018;141.
[7] On the Autism Spectrum, 1.
[8] It is important to consider familial and social relations—particularly when they function as supports. However, the system must build in safeguards to ensure people (including adults) are not made to over-rely on family approval and control in order to be included in the community on equal terms.

These considerations should inform the necessary elements included in all supported housing arrangements (see Figure 1 below).

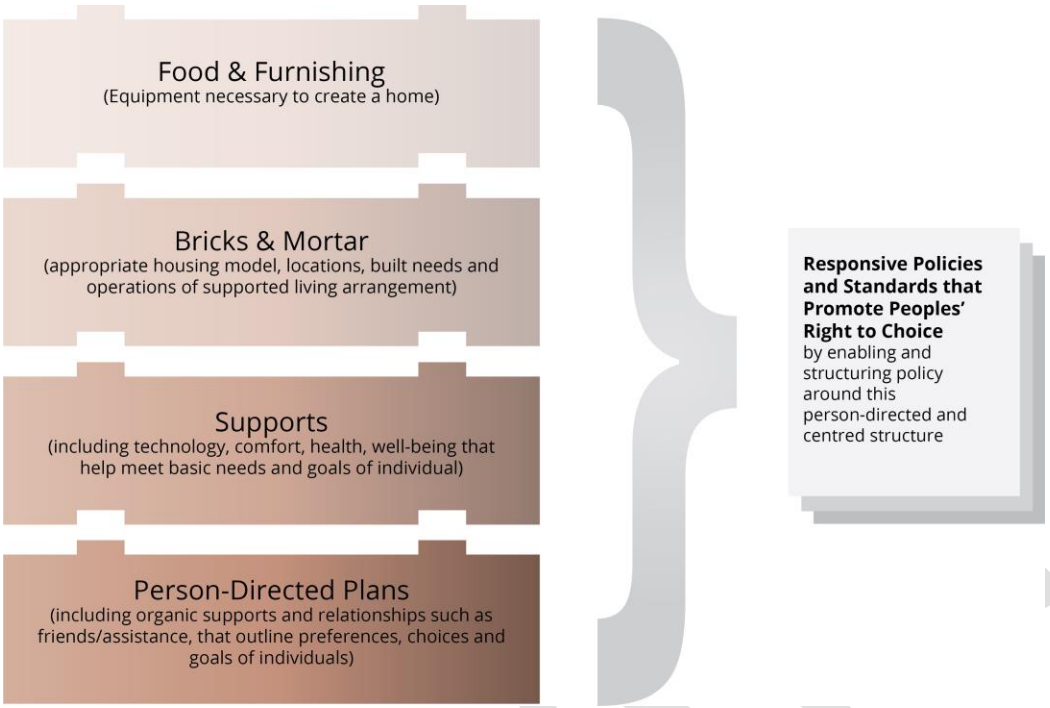

Figure 1: Necessary Elements of Supported Housing Arrangements with Person-Directed Plans at the Foundation

Thankfully, there are signs of change and increasing awareness of these considerations in Nova Scotia. The current service system still includes traditional residential services provided by agencies that are typically funded by the Department of Community Services (DCS) to provide both supports and housing in the same organization. In some cases, the Nova Scotia Department of Health and Wellness (DHW), the Nova Scotia Health Authority (NSHA) and/or the IWK partner with DCS to provide support and residential funding for individuals with complex needs. At this point in time, the criteria for dual DCS/DHW funding is not known, nor is it known how many individuals might qualify for or currently receive this type of funding.

Recent years have seen the emergence of self-directed, individualized funding that separates the provision of housing from the provision of support services. While the primary source of funding is still DCS, funds in this form go directly to the individual rather than through an agency that provides housing and supports jointly—providing the flexibility for the person to change their living arrangement to meet their needs. DCS may not be the *only* source of funding in these cases, where a mix of public and private funding might be used; which must be noted because it does mean there is potential for social inequalities to shape the distribution of funds and their application. Nevertheless, direct or individualized funding is the start of an important foundation, which must be further developed, to ensure that flexibility in supports and housing meets individuals' needs, and allows individuals' and their kinship supports to define the best supports for them, rather than forcing them to fit into prescribed housing and support regimes.

Having more options creates exciting opportunities for change, but it also brings its own challenges. Putting it simply, for individuals and families navigating the evolving landscape of supported housing options, and for service providers, government, private sector developers, financiers, and other parties, there are numerous considerations and constraints that now, more than ever, require awareness, deliberation and decisions. All stakeholders in the supported housing system have more choice, but this also means they have more responsibility and uncertainty and have to navigate more complexities on an individual level, with little infrastructure in place to help.

The identification of constraints and complexity does not indicate that a person-centred system is unattainable, even in the short term. The *Roadmap* and the broad consensus, seen across stakeholders in its assessment and goals, should make clear that there is a gap between the existing system and a better one—one that puts people with disabilities at the centre—and that the primary challenge before us is identifying the **means for moving toward building that better system.** To do that, we must ask ***how we, as a community of persons that need support, and are providing support,*** can work and collaborate to realize a person-centred supported housing system that enables individuals and their families to make the choices that contribute to their quality of life and help them participate fully in their communities. As *On the Spectrum* notes*:*

> In Nova Scotia, self-advocates, along with the support of their family and kin, want to work with vested stakeholders and investors, to create and inform real choices about where they will live, who they will live with, and how they will live in their communities. Housing solutions and in-home supports or interventions for people with ASD need to be informed by, as well as be developed and implemented in partnership with, members of the community and the organizations that serve them. The transition into adulthood (and into the community) for individuals with ASD, like all developmental disabilities, requires meaningful community options, and economically viable social policies.

Our challenge is not to agree on all things or on the ideal alignment of resources and efforts, or an ideal system. Instead, accepting that "person-centered" and self-directed community living are the basic rights-based foundation for building to better, our immediate challenge is to ask, "How can we work toward them together, and who wants to join us in this movement?

Supported Housing Summit Preparation and Process

To begin this dialogue, Autism NS invited a group of individuals and family members interested in supported housing, service providers, officials from government social and human services, as well as residential housing agencies and some private sector stakeholders, to an IDEAS session on how to improve the supported housing system. The session, held on April 24, 2019, invited participants to brainstorm:

1) The frameworks that could help inform individual, policy level and collaborative discussions;
2) Defining and expanding the options for people looking for housing and supports in the developmental disability community;

3) Ideas for how to best overcome the barriers and limiting realities that limit individuals' opportunities to live in supported housing;
4) Identify key areas where reform or innovation efforts could be targeted to help expand the capacity to support and the housing models available to individuals.

Several shared beliefs emerged[9] from the IDEAS summit, but the most prominent was the need for supported housing to go beyond the physical home and encompass the unique needs and desires of the individual. Participants identified the need for supported housing to be shaped around the individual and not the other way around, and for the supports to not be over-prescribed or medicalized in their delivery—in other words, participants articulated a shared desire for a more person-centred supported housing system.

In this ideal system, participants envisioned supported houses offering a balance of intervention and privacy, such that individuals living there could have freedom and autonomy in their daily lives. Autonomy was also identified as crucial for individuals to have beyond the home, so they have the choice to participate in and be a part of their community. To achieve this vision, and to assess progress toward it, participants believed that stakeholders had to initiate ongoing, transparent collaboration and communication with one another about a number of priority issues and means to address them. Those issues included:

1. Lack of funding and actual housing options (particularly in rural areas),
2. Inaccessibility of resources such as funds, models, community-based supports, in-home supports etc.
3. Presumed incompetence of individuals being supported
4. A lack of education and training for staff, families and other stakeholders in the system

To combat these issues, participants agreed that best practices would need to be established based on concrete recommendations with clear standards in reporting and accountability. Doing so, the session's discussions indicated, would help supported housing in Nova Scotia to become a proactive rather than a reactive system and practices.

The session's discussions will be continued through consultations conducted through the summit website, even past the second event in October 2019. This event, which Autism NS is calling the SOLUTIONS session, will be used to present the "collective findings and learnings" arrived at over this several month process. Taken as a whole, the preliminary materials, IDEAS session in April, SOLUTIONS session in October, and Consultation Period between these two bookend events, will all be used to reach the following outcomes:

1) Create Historic Documents: Create a White Paper and Documents of Reference that will provide a touchstone for the future of autism and developmental disability supported housing planning;

[9] During the summit, data and information were collected in multiple ways (self-report, group discussions, graphic harvesting, and through purpose-built tools) by 11 designated independent recorders. This allowed for post-session analysis and reflections on the issues and beliefs that emerged during the summit.

2) **Unite the Community:** Build momentum for housing solutions reform as a priority issue through a multi-stakeholder, collective impact framework;
3) **Build the Framework of Collaboration between all levels of Government and Stakeholders** toward sustainable, person-directed, rights-based solutions that create the conditions for individuals to lead good quality lives;
4) **Provide Resources** for Individuals, Families and Communities exploring housing, support, funding and other options; help direct work at a grassroots level, and in turn influence policy.
5) **Creating innovations** with a person-directed approach as people move towards independence.

The history of community feedback, consultation, roadmaps, and think pieces has provided a clear compass pointing the way we must go to build to better. In the rest of this paper, we present a detailed examination of the current context for supported housing, from the elaboration of who needs supports, to the critique of existing policies and programs, all with the aim of informing our community—including people with autism and developmental disabilities, their families, service providers, advocacy organizations and governments—about where we are in order to plan how to get where we need to be.

1.0 The Current Demand for Supported Housing in Nova Scotia (NS)

Determining exactly how many people with ASD, or any other Developmental Disability, want or need supported housing in Nova Scotia is important for any discussion of system change, but also inherently difficult. At a population level, supported housing "demand" has two main components: 1. Demand for the physical space or "bricks and mortar", and 2. Demand for the support and assistance to live well. At an individual level, person-centred supported housing is about having a choice about where you live, choosing who you live with, and determining how you want to live. At the system level, ideally, a network of services and support fulfills both population-level demand for supported housing and individuals' hopes and dreams for a good quality of life.

Currently, no reports have been written describing the current demand for supported housing or determining the "future demand" in Nova Scotia. The 2013 "Roadmap"[10] does not delve into the logistics of how many people in Nova Scotia need supported housing based on Nova Scotia's population, what services are provided and needed, or individuals' support needs to live well in supported housing.

In the following section, we will estimate the number of Nova Scotians with ASD and other developmental disorders who need supported housing based on population and health record data. These estimates will be imperfect as they rely on prevalence rates rather than actuals and population data that was not collected for this purpose, but the exercise provides us with a useful estimate for discussion purposes.

1.1 ASD/DD Demographics in NS: Known and Unknown

The most recent prevalence rate published by the Public Health Agency of Canada (PHAC) suggests that the prevalence rate for ASD[11] is 1 in 66 in Canada and 1 in 68 in Nova Scotia.[12] Looking only at ASD diagnoses, we estimate there are at least 13,582 Nova Scotians with a diagnosis based on the DSM 5[13] (see Appendix A for a more detailed explanation). The estimate for the province suggests that there are 826 emerging adults, ages 20 to 24 years old, 790 young adults, ages 25 to 29 years old, 1,526 adults, ages 30 to 39 years old, 5,016 older adults, ages 40 to 64 years old, and 2,703 seniors, ages 65 years and over (see Appendix B). Thus, there are at least 10,860 adults living on the spectrum in NS that currently and likely want or need some form of support–from minimal to intensive, either living with family members, in their own homes, or in supported housing (Hutchinson et al., ANS, 2019, Appendix A). This does not

[10] Choice, Equality and Good Lives in Inclusive Communities. A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program. 2013

[11] PHAC and the Nova Scotia Health Services (DHW/NSHA/IWK) use the 2013 DSM 5 definitions for ASD, DD, and ID.

[12] https://www.canada.ca/en/public-health/services/publications/diseases-conditions/understanding-national-autism-spectrum-disorder-surveillance-system-report-2018.html

[13] PHAC and the Nova Scotia Health Services (DHW/NSHA/IWK) definie ASD, DD, and ID using Diagnostic and Statistical Manual of Mental Disorders 5th Edition.

include the number of Nova Scotians under age 20 who will want supportive living arrangements in the next decade (~2,722).

It is also important to highlight the estimates of people with developmental disabilities living in NS as ASD fits within the mantle of developmental disorders and because of its significant co-occurrence with other developmental disabilities, such as intellectual disability. The only available data source on the number of people with developmental disabilities in Nova Scotia was taken from health services data in 2011. It is based on the cumulative incidence of developmental disabilities, which includes people with ASD, and estimates that at least 28,736 people with developmental disabilities live in NS[14] (see Appendix C).[15] Considering the prevalence estimates for ASD from PHAC, **we can reasonably assume that there are *at least* 10,000 or more adults living on the spectrum in Nova Scotia; and by subtracting this estimate from 22,986 (noted above) would suggest there are at least 12,000 or more adults with other developmental disability(ies) also living in Nova Scotia**.

1.2 Need for Supported Housing Based on NS Demographics: Known and Unknown

In addition to the lack of basic prevalence data, Nova Scotia also lacks a clear picture of the current and potential demand on the supported housing system, or of the "demand" on essential services provided by health and justice departments to keep people in their homes and out of institutions. Currently, there is no data in Nova Scotia on how many people with ASD or DD need support (or the amount of support), how many are living independently, and the extent to which they want or need formal community living supports (e.g., preferences around the types and intensity of assistance, where they live, and whether it is sustaining a good quality of life).

What is known is that young adults with ASD are more likely to live with their parents and least likely to live independently after leaving high school as compared to those with other types of disabilities.[16] Only about 17 percent of young adults on the spectrum ages 21 to 25 have ever lived independently. By comparison, nearly 34 percent of their peers with intellectual disability have lived independently. Since leaving high school, most young adults with autism — nearly 9 in 10 — have spent at least some time living with a parent or guardian, according to the study. And most have never tried another living situation. Young adults with ASD resided with a parent or guardian at higher rates and for longer periods of time after leaving high school than young adults with intellectual disability. Moreover, young adults with an ASD had the highest rate of

[14] This estimate may be higher or lower as it depends on health care professionals documenting the diagnosis, which may or may not be deemed relevant to the type of health service that is being provided.
[15] Asbridge, M. et. al. (2011). Dalhousie University, Department of Community and Health Epidemiology. This estimate includes a provincial breakdown by sex and geographic location but provides no breakdown by age. However, much like the census data estimate for ASD, this number is likely to reflect a 20/80 split in the population-based on age, with 20% (or ~5,750) under the age of 20 years-old and 80% being 20 years and older (~22,986).
[16] Anderson K., Shattuck P., Cooper B., Roux A., & Wagner M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. Autism 18(5); 562-570. Note the analysis was done using the US National Longitudinal Transition Study-2 (NLTS2) database. Data were collected in five waves, 2 years apart, from 2001 to 2009 from 620 participants with ASD, 450 with intellectual disability, 410 with learning disabilities, and 380 with emotional disturbance.

supervised living arrangements and the lowest rate of independent living after leaving high school.[17]

A 2011-12 survey conducted by the Massachusetts-based Autism Housing Pathways found that only about 3% of respondents with autism were completely independent in both their Activities of Daily Living (ADL) and Instrumental ADLs (including handling finances, shopping, and taking medication). The rest presumably need some supportive services in their homes.[18] These findings are significant, as these skills are highly correlated with both employment and quality of life in adulthood. Also, these findings are roughly consistent with another Arizona based survey and report that showed only 4% of autistic adults living independently; another 2% living with a spouse, partner, or a family member who was not a parent or guardian. [19]

On the basis of these US findings, it is fair to assume that at least *90 percent of Nova Scotian adults with ASD (an estimate of 9,775 based on 10,860) and as many as 80 percent of Nova Scotian adults with DD (an estimate of 9,700 based on 12,126) are likely to need some form of supported housing*. This means at least 23,000 adult Nova Scotians with ASD/DD may need some form of residential/community living support. Given the existence of growing waitlists, a large proportion of the people who need living supports have none. There are two groups of people who are currently underserved in Nova Scotia: those who qualify for DSP funding but require the types or intensity of support that are currently unavailable in typical "residential models" (even small option homes), and those who do not qualify for funding and are not able to access DSP streams of housing support such as independent living because their support needs are deemed too low. Currently, it is not known how many Nova Scotians with ASD/DD need support at home or a different home and are not receiving them, making it almost impossible to understand from a population level what is needed or to do any forecasting or planning to meet people's needs so they can live a quality life.

To provide an estimate of how many people may need a supports and housing in Nova Scotia, we have compared the number of adult Nova Scotians with the number of funded residential spaces[20] in the province (see Table 1 below). Service gaps are apparent: residential availability varies across Nova Scotia, covering from as little as 6% of the population in Halifax County to 30% in Pictou County with an overall coverage of 13% in the province. This leaves the majority of the ASD/DD population (~87%) without any available residential service options.

[17] Anderson K., Shattuck P., Cooper B., Roux A., & Wagner M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. Autism 18(5); 562-570. Note the analysis was done using the US National Longitudinal Transition Study-2 (NLTS2) database. Data were collected in five waves, 2 years apart, from 2001 to 2009 from 620 participants with ASD, 450 with intellectual disability, 410 with learning disabilities, and 380 with emotional disturbance.

[18] Boyle, Catherine, "Housing needs and desires in the Massachusetts Autism Community," Autism Housing Pathways Building a Home Conference; September 29, 2012. (http://autismhousingpathways.net/wp-content/uploads/2014/05/AHP_Survey_results.pdf)

[19] Klinger et al., "Correlates of Middle Adult Outcome: A Follow-up Study of Children Diagnosed with ASD from 1970-1999," *International Society for Autism Research,* 2015 (https://imfar.confex.com/imfar/2015/webprogram/Paper20033.html)

[20] Residential spaces include small option homes, group homes, developmental residences, adult residential centres, and regional rehabilitation centres.

Table 1: Nova Scotia ASD/DD Population and Number of Residential Spaces by County

Nova Scotia Counties	NS ASD/DD Population	Adults (80%)*	Adults Needing Support(75%)**	# of NS Residential Spaces***	Coverage by County
Lunenburg, Queens	1723	1378	1034	131	13%
Shelburne, Yarmouth, Digby	1132	906	679	118	17%
Annapolis, Kings	2353	1882	1412	306	22%
Colchester, Hants	2208	1766	1325	100	8%
Cumberland	781	625	469	98	21%
Pictou	897	718	538	159	30%
Guysborough, Antigonish, Richmond	1112	890	667	59	9%
Inverness, Victoria, Cape Breton	2970	2376	1782	399	22%
Halifax	14414	11531	8648	478	6%
Unknown	1146	917	688		
Totals	28736	22989	17242	1848	13%

*Based on Nova Scotia's census data which shows that 80% of the population is over the age of 20.
**Based on adult outcome research and conservatively estimated to reflect the number of adults in Nova Scotia needing support.
*** Residential spaces include small option homes, group homes, developmental residences, adult residential centres, and regional rehabilitation centres.

These estimates suggest there are not enough housing spots in all communities and that some communities are much worse off than others. These realities unfairly limit peoples' choices and force individuals with ASD/DD who want or need supported housing to move away from their families and friends. This means that people may be forced to leave their communities, relationships, and the people that care about them and for them. Not coincidentally, this was a reoccurring theme at our Supported Housing Summit, encompassing varying disability groups, including complex physical disability needs.[21]

> Risk: Individuals with supported housing needs may not receive it in their county or region because no residential options are available nearby, or their support needs are either too minimal or too high based on what is available. Given the gap between how many people need a residential option and what is available, it is more likely, they are on a waitlist, or they have given up hope that anything will come their way.

Recommendations For 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

[21] https://supportedhousing.ca/event-report

need for supported housing, with which to inform any planning around supported housing in Nova Scotia.

2.0 Current Context for Supported Housing in NS: Segmenting the Demand

To understand how the demand for housing interacts with demand for disability support services and resources, it is helpful to divide the population that would "need" housing into roughly four major segments. They are:

1. Individuals with unmet and unknown disability support needs (those unconnected to funding and services and "at-risk" for unknown housing needs and unmet support needs).
2. Individuals connected to the disability support system, perhaps receiving some funding from DCS or DHW/NSHA and possibly not on a waitlist for residential supports (who might have unmet housing needs and support needs that would challenge existing support structures).
3. Individuals with disability supports and connected to waitlists (those with unmet support and housing needs, but who are waiting to access residential services).
4. Individuals in existing large congregate, institutional, inappropriate, or undesired "placements" (those deemed as receiving services but with unmet support and housing needs).

This segmentation of demand matters because the needs of individuals can vary dramatically, with some people requiring intense, multi-support-worker arrangements in highly customized built environments, while other people may require regular check-ins or could function with a higher level of independence if connected to some modest life and social skills support. Regardless, there remains a huge amount of unmet need, not just for brick-and-mortar housing, but for access to adequate and appropriate supports.

2.1 NS Disability Support Program Policy and Accessing Supported Housing

For individuals with disabilities, it is the amount and type of support needed that currently predicts which types of residential options are available to them. Individuals are assessed based on IQ, diagnoses, health status, medical conditions, behaviours that challenge, their ability to carry out activities of daily living (e.g., personal care), instrumental activities of daily living (e.g., shopping, budgeting, and money management), and to manage safety risks. It is important to note that this assessment is conducted by a DCS care coordinator with the individual and family members. Currently, DCS does not use a recognized standardized assessment tool to determine an individuals' required level of support need, creating a high reliance on the knowledge, experience, and discretion of the care coordinator. Individual support needs are assessed through an interview and scored on a range from level 1 to level 5. Levels of support are defined as follows: Level 1 is minimal support, level 2 is moderate support, level 3 is high support, level 4 is enriched support, and level 5 is intensive support. [22]

[22] https://novascotia.ca/coms/disabilities/documents/Disability_Support_Program_Policies.pdf

Whether or not a person is deemed eligible to receive residential services depends on several other factors—some well-known, and some unknown and unclear for applicants and other stakeholders in the system. The policy states, "The following criteria will be considered when referring an individual to a service provider:

a) the type of support option available and applicant's preferences;

b) the applicant's priority;

c) the applicant's assessed level of support need;

d) the date the applicant was added to the service request list;

e) the service provider's expertise;

f) accessibility requirements; and

g) support needs of other participants in the home." [23]

Several unknowns limit the understanding and effectiveness of this policy, and create conditions for exclusion of individuals who desperately need and qualify for DSP streams of funding and residential supports. For example, 60-70% of Nova Scotians with ASD may be deemed ineligible for DSP funding because they don't meet the IQ criteria (only 37% of females with ASD and 30% of males with ASD also have an intellectual disability).[24] Additionally, DCS does not provide a publicly available inventory of the number and types of support options available to applicants. Applicants are often unaware of what is available, thus limiting their ability to make informed choices about their preferences.

While applicants are informed individually about their assessed level of support and priority, there is no clear public, aggregate accounting of how many people are at what level of support or priority level in Nova Scotia, and what services or supports are available to individuals at those levels.[25]

Importantly, the following funding programs are currently offered by DSP in Nova Scotia, which are applied to residential or other supported housing arrangements:

1. **Direct Family Support for Children** - Direct Family Support for Children (DFSC) and Enhanced Family Support for Children (EFSC) provide funding to enable families to support their child with a disability at home. DFSC and EFSC provide funding for the purchase of respite services to assist with scheduled breaks for family caregivers. An enhanced funding component may be available for children and families who meet EFSC eligibility criteria.

[23] https://novascotia.ca/coms/disabilities/documents/Disability_Support_Program_Policies.pdf

[24] Christensen DL, Braun KVN, Baio J, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveill Summ*. 2018;65(13):1-23. doi:10.15585/mmwr.ss6513a1

[25]

These figures are typically publicly reported based on specific requests, such as those by the ongoing Human Right Inquiry, and interested others (e.g., see Appendix D for an excerpt from a 2017 report outlining the number of people on the waitlist, assessed level of support, and diagnosis).

2. **Flex Program** - The Flex Individualized Funding program provides supports and services to adults with disabilities who live at home with their families or who live independently with support from their family or personal support network. The program provides self-directed and self-managed funding to eligible participants.
3. **Alternative Family Support Program (AFS)** - provides support for persons with disabilities to live in an approved, private family home. The participants must be unrelated to the AFS provider.
4. **Independent Living Support (ILS)** - provides funding for hours of support services from a Service Provider, based on the assessed needs and circumstances of an eligible participant who is semi-independent but requires support to live on their own.

2.2 Types of Residential Spaces Provided Through DSP Funded Service Providers

The vast majority of the "spaces" that can be counted as current supported housing capacity, through the DSP, are Licensed Homes for Special Care[26] –which provide support and supervision in homes with three or more spaces (beds). There are 81 independent service providers in Nova Scotia, non-profit and for-profit, which deliver residential support with funding from the DSP. Some service providers serve a total of 3 people while others serve over 100 people (see section 2.2 for descriptions).[27] Each of these providers has its own policies and practices, as well as administrative personnel and governance structures. Licensed Homes for Special Care include the following types of residential options (also see Table 2 below):

1. **Small Options Homes** - three to four persons are supported by qualified care providers in a community home. The home and the staffing are provided by various private service providers. There are 213 small options in Nova Scotia providing 692 spaces (this includes 35 spaces for children).[28]
2. **Group Homes and Developmental Residences** - provide a continuum of developmental rehabilitation programs for individuals with disabilities within a 4 to 12 persons residential setting. There are 47 group homes (300 spaces) and 52 developmental residences (269 spaces) in Nova Scotia providing 569 spaces.[29]
3. **Adult Residential Centres ("ARC"):** provide long-term structured supports and services, typically to twenty or more adults with disabilities, to enhance their development of interpersonal, and activities of daily living skills. Approved staffing is provided at all times by on-site professional staff. There are 7 ARCs in Nova Scotia providing 368 spaces.[30]

[26] https://novascotia.ca/just/regulations/regs/hsc7393.htm : Nova Scotia's Licensed Homes for Special Care Act was passed in 1977 and last amended in 2012. It contains outdated language and practices and reduces "living in the community" to "placement" in a "bed".
[27] https://www.disabilityrightscoalitionns.ca/wp-content/uploads/2019/03/VI-A-67-DCS-DSP-Transformation-ARC-RRC-Current-State-Overview-FINAL-.pdf
[28] DCS Directory of Licensed Homes for Special Care (January 10, 2019)
[29] DCS Directory of Licensed Homes for Special Care (January 10, 2019)
[30] DCS Directory of Licensed Homes for Special Care (January 10, 2019)

4. **Regional Rehabilitation Centres ("RRC")**: provide both rehabilitation and developmental programs, typically to twenty or more adults with disabilities, who require an intensive level of support and supervision related to complex behavioural challenges and skill development needs. Approved staffing is always provided by onsite, professional staff. There are 4 RRCs in Nova Scotia providing 185 spaces.[31]

Table 2: Facility Types and Residential Spaces in Nova Scotia as of January 2019[32]

Facility Type (FT)	# of FT	# of spaces by FT	% of Total Spaces by Total FT Spaces
Small Options	213	688	37.8%
Group Homes	47	300	16.6%
Developmental Residences	52	277	15.2%
Adult Residential Centre	7	368	20.2%
Regional Rehabilitation Centres	4	185	10.2%
Totals	344	1818*	100%

*This total excludes 30 respite beds.

Table 2 conveys a good news, bad news story. The good news is that in Nova Scotia, the largest proportion of residential spaces are provided in small options homes (37.8%). The bad news is that most of these smaller homes are located in the urban areas of Nova Scotia. Further, the second largest number of spaces are provided in adult residential centres (ARCs: 20.2%), which, depending on the service provider, may support over 50 people in one facility. These are large congregate settings and by all accounts are defined as institutions. Regional Rehabilitation Centres (RRCs: 10.2% of total spaces) are also large congregate settings. Adding ARCs and RRCs together, at least one-third of the total residential spaces provided in Nova Scotia are provided in larger settings which are more akin to hospitals than to home-like settings in neighbourhoods. All of these large congregate settings are located in the rural areas of Nova Scotia, possibly indicating that if individuals with ASD/DD are growing up in rural areas and want to remain close to their family and community, the only readily available supported living option is an institution.

In addition to these large congregate settings, people with DD and health care needs, regardless of their age, may be placed in senior care facilities which are primarily funded by the Department of Health and Wellness (DHW). It has been noted that these arrangements are often used as a stop-gap due to the lack of DCS community-based options. This was a key piece of feedback from a number of tables and participants at the Ideas Summit in April, which showed the lack of options in the existing "stock" of places and spaces,

> …too often meant people were being "placed" in an ill-fitted home that could be a poor match with housemates, or with a support structure already in a home and, in some cases, these dynamics could create unsafe living conditions. This lack of control was another sub-theme […]; a lack of control over where one was "placed", how they would continue to not only survive but thrive in their personal development

[31] DCS Directory of Licensed Homes for Special Care (January 10, 2019)
[32] DCS Directory of Licensed Homes for Special Care (January 10, 2019)

and how they would get around the broader community were all identified as significant gaps."

However, because these arrangements are siloed off from DCS and are funded through DHW/Nova Scotia Health Authority, it is not known how many people are affected or whether they are given a choice to move to more appropriate living situations when a suitable community-based home becomes available, or offered the opportunity to help develop, on their own or with family and others, a more appropriate arrangement.

2.2.1 Individualized Homes and Shared Support Residential Options

An important way of categorizing supported housing options for the ASD community, as well as the developmental and physical disability community, is to divide them into two main types: scattered-site and congregate. In the international literature, these settings are often referred to as "dispersed" or "scattered-site" and "clustered," or "congregate", respectively.

In **scattered housing,** people with disabilities live in apartments or homes located in neighbourhoods not specifically intended only for individuals with disabilities.[33] They own or rent housing themselves. Residents live alone or with a small number of roommates.[34] They may receive nursing care, assistance with activities of daily living, and/or other services, but the agency providing support services is not generally involved in residential provision (Larson et al., 2013). This model effectively splits the bricks-and-mortar from the supports. Small option homes and smaller settings (one individual living in an apartment with occasional support, e.g.) are the exemplars of scattered housing in Nova Scotia.

In **congregate housing,** multiple individuals with disabilities reside in a single building or complex. Typically, residents receive services through the agency that owns the residential facility (Larson et al., 2013). *Congregate housing yoked with support is the dominant residential service framework in Nova Scotia.* Because of this, the amalgamation of service and brick-and-mortar housing is the dominant service model and structure in Nova Scotia's current state, and is seen in group homes, developmental residences, ARCs, and RRCs.

Studies show that the scattered-site housing models optimize the autonomy for individuals with disabilities, integrating residents into the surrounding community, involving the individuals with disabilities in staffing choices, and creating access to opportunities for broad participation in the community. As such, scattered-site options more easily reflect the QoL and person-centred planning principles Nova Scotia should move toward. For example, research in Europe and North America has shown that those who live in dispersed housing schemes have larger social networks, live in home-like settings (which was a point of focus among many of the Summit participants concerned with removing institutional feelings and conditions), participate in more activities in the community, and have more opportunities to make choices, than do residents

[33] Mansell & Beadle-Brown, 2009
[34] Burchard, Hasazi, Gordon, & Yoe, 1991

living in congregate arrangements.[35] But growing the number of such arrangements will require careful planning and resource allocation.

Specifically, the increasing demand for scattered and individualized supported housing arrangements requires a Quality of Life lens and accountability framework. A QoL lens is fundamental, because it creates a system for guiding the development of new innovations that respect individuals' wishes, decision making, and choices, building towards a fuller citizenship that we all expect in our lives. A QoL accountability framework tracks concrete outcomes and determines which individualized housing arrangement models work in particular circumstances.

2.3 Multiple and Hidden Waitlists

Demand for both the scattered and congregate-type arrangements in Nova Scotia outstrips supply. However, t**here is a common misperception that a person seeking supported housing is entered into a singular "waitlist," but based on past and recent information from DCS no singular Provincial Waitlist exists.** Instead, what we have is a scattered series of waitlists across housing types. As a 2008 Report on Residential Services outlined:

> As a result of the closing of large institutions, other residential options in communities for persons with disabilities quickly filled. Without appropriate resources in the community, long waiting lists for these services ensued. This situation was being experienced by most jurisdictions across Canada, North America and Europe as the deinstitutionalization movement took precedence. In Nova Scotia, *the Homes for Special Care Act and Regulations* governs the operation of homes that provide care and support to persons with disabilities and seniors. This legislation pertains to homes where four or more persons are supported. In an attempt to respond to the ever-increasing pressure in the community, Small Option Homes for up to three individuals were developed… to provide care and support to individuals with mild to severe disabilities. In the meantime, the waitlists for residential services across the province continue to grow. (4)

And as the report later notes:

> Admission to a residential option occurs through the DCS regional offices. The person and/or family may indicate a preference of type of setting, as well as location. Once assessment and determination of program eligibility is completed, the applicant's name is placed on a waitlist until a vacancy becomes available in an appropriate residential setting. To the greatest extent possible, the individual's choice will be considered. Each regional office maintains its own waitlist and manages the utilization of all residential resources in the region. (13)

Since this 2008 report, the structures and funding of the DSP system have been transforming slowly, but the system for referrals and eventual "wait-listing" remains effectively the same. What has changed, and significantly, is the amount of demand. The 2008 report was able to

[35] Emerson, 2004; Emerson et al., 2000; Mansell & Beadle-Brown, 2009; McConkey, Abbott, Walsh, Linehan, & Emerson, 2007).

compile the four regional waitlists to come to 390 individuals waiting for admission to residential arrangements. However, using DCS's waitlist numbers from 2017 and **the most recent numbers that were corroborated by evidence submitted** in a recent Human Rights Tribunal, the sum of all waitlists **has grown substantially from 390 in 2008 to at least 1,560 in 2019** and that these people remain there for a significant period of their lives, or indefinitely.[36] Unfortunately, most of these waitlisted people are waiting for small option homes (n=1047). Given the current level of investment in small option homes, the likelihood of meeting these requests is nil, yet DCS continues to offer this option while providing no indication of when or where these requests will be honoured.

Interestingly, DCS notes that 1033 of the 1560 on all waitlists combined are DCS participants currently receiving some type of DCS funding or direct support, but requesting a different support option. Over half of the participants (i.e. 569) in this group are receiving DSP Flex funding (note: Flex is a direct benefit funding program and is discussed in the next section of this paper). We know that Flex has a total of 1300 participants; that 569—over a third—are requesting a different program suggesting that direct benefit funding is not meeting participants' needs, or it may be used as a stop-gap until a more preferred service becomes available (e.g., direct support services). Of the 1560 waiting for a supported housing option, the remaining 533 people are eligible for DSP support but not receiving any DSP services. Based on the data, most of these applicants are receiving no services at all (e.g., 163 are living alone or 113 are living with family, living in a hospital or nursing home waiting for DCS receiving services-- 76 are hospitalized and 22 are living in a nursing home), or receiving some form of income assistance (64 are receiving ESIA).

2.3.1 Institutional Waitlists

The scenario described above is only part of the "Waitlist" picture. There is also a **backlog of over 500 persons** in the DSP living in Adult Residential Centres and Regional Rehabilitation facilities, who either wish to move to alternate or more appropriate arrangements or are slated to move with the closure of these institutions (for an overview see Table 2 and Appendix D). While many of these individuals are not likely on any of the waitlists that exist (e.g., there are only 168 are included in the current count of 1560 on the waitlist[37]), they must be counted as part of the demand. Since 2013, Adult Residential Centres have decreased by 106 spaces and Regional Rehabilitation Centres have decreased by 5 spaces.[38] Granted, the majority of the people who vacated these spaces were moved to more appropriate arrangements, however they moved to the same arrangements that people who are the waitlist are waiting for too. And then we must also add to this list the more than 200 persons with ASD/DD and complex physical disabilities in DHW and NSHA managed facilities that were never meant for long term housing—such as

[36] MacLean *et al.* v. Crown: Decision Of The Board Of Inquiry On Prima Facie Discrimination [March, 2019], 67.
[37] 62 people in RRCs or ARCS are on the waitlist because of the three-year moratorium on placements in institutions, and 54 in ARCs and 52 in RRCs requesting a different service, for a total of 168 now living in institutions but wanting/needing different supports.
[38] DCS Directory of Licensed Homes for Special Care, October 23, 2017 (the figures combine both adult and children SOs and include both licensed and unlicensed SOs).

nursing homes and hospitals All of this means that we must take this defined source of demand and combine it with those connected to DSP and on the waitlist but not admitted to housing.[39]

Adding these together it is likely that the real number of people waiting for housing is at *least* 2000 people, and as many as 2300 (1560 on the combined regional waitlists, 500+ in large congregate settings, and 200 in DHW/NSHA facilities). Even the high end is conservative, as it does not include the number of people who have opted to simply not go on, or do not qualify to be on, a waitlist.

2.3.2 Unknown or Hidden Demand: Beyond Institutions and the Waitlist

The question of demand becomes even more complex when we consider the hidden, but no less real, demand generated by:

1. Individuals unconnected (because of non-qualification or because of non-access) to DSP; "at-risk" of or already having unmet support and housing needs; and
2. Individuals connected to DSP but either unaware of the process for "getting on" the waitlists or disengaged for a variety of reasons.

In the second group are parents who are looking after adults with disabilities but who are discouraged by the length of the waitlist and may not be applying or given up their advocacy efforts for a variety of reasons. This population is a particularly "at-risk" segment, because their reliance on organic, usually family/kin as support, makes them vulnerable to even the slightest re-alignment of a caregiver's world—to say nothing of the very real possibility of family or kin aging out of their ability to support a person.

In the first group are individuals with ASD (often those *without* a co-occurring, or whom border on having an intellectual disability) who are not accessing disability supports program but still need supports, and are in core housing need. The group includes: those who have not been assessed as eligible for disability supports even with a diagnosis, and those who have not been able to *acquire* a diagnosis for reasons of affordability and availability of practitioners. Even with a diagnosis of ASD, there are currently, 60-70% of Nova Scotians with ASD who may not be eligible for DSP funding because they don't meet the IQ criteria (only 37% of females with ASD and 30% of males with ASD also have an intellectual disability).[40] There are, of course a host of other reasons that individuals may be unable to connect with the DSP, including lack of parental or familial awareness of the system.

> Risk: The assessment tools used to determine eligibility for the Disability Support Program are designed in such a way that people who have ASD , who do not have an intellectual

[39] MacLean v. Crown, 67, The Deputy Minister noted that "the formal waitlist may be shorter than the total of those who actually want placement. There may be parents who are looking after disabled offspring who may be discouraged by the length of the waitlist and may not be applying. The growing waitlist is an expression of a need that the Province is not meeting."

[40] Christensen DL, Braun KVN, Baio J, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveill Summ*. 2018;65(13):1-23. doi:10.15585/mmwr.ss6513a1

disability or who would be part of the "borderline ID" diagnosed population, are being deemed ineligible for needed and necessary disability support programs.

People who do not get diagnoses are pushed to the complex ESIA funding structures, which are inadequate for the additional expectation of funding any kinds of supports. This is a concern that has been recognized in other jurisdictions. The American National Autism Indicators Report in 2018 noted that across most jurisdictions in the United States, the number of individuals with a co-occurrence of ASD and an ID [intellectual disability] has been shrinking "since 2002 and is currently estimated at around 30% of children with ASD." Yet, the group of people with ASD who receive DD (Developmental Disability) services, however, tend to have a much higher rate of ID."[41] It is therefore very plausible that this same phenomenon is at work within the Nova Scotia system--the evidence to test this could be easily gathered--which means that a significant number of individuals with ASD who do not meet the DSP criteria are struggling to access funds for supports that would help them explore or build the capacity for increased, if still supported, independence.

2.3.3 Risks around "The Waitlist(s)"

Waitlists are multiple and extensive, and many people are waiting for a "bed" to come up, with little knowledge of what that would look like. At the same time, there are many individuals actively supporting persons with disabilities who have little or no understanding of how to become connected to a waitlist or what it means to be *on a waitlist.* While government and some residential service providers have a better sense of what the "waitlist" is for them locally, and particularly for those who have applied to program funding streams provided through DSP, as the above demand section outlined in more detail, this does not capture nearly a full picture of the latent demand and unmet need for housing and supports.

While the term "The Waitlist" is well known, there is no clear understanding of what "the waitlist" is, and how many there are and which one you are on, as well as where you are on them, and how residential providers decide how individuals who are at front are fitted into the system.

Risk: There is a lack of clarity around what "The Waitlist", where one is on it, and little transparency on how ones' status or position on the list is assessed and prioritized by government or service providers.

Risk: The focus on a system level of housing, rather than a person-directed individualized approach to identifying a suitable home life, has created the conditions where the common language used in supportive housing is of "placements" and "beds", which effectively turns homes into little more than housing spots. The risk in this is that the supportive housing system becomes an institution in and of itself, working outward from the availability of "spaces" and

[41] Roux, Anne M., Rast, Jessica E., Anderson, Kristy A., and Shattuck, Paul T. *National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood.* Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2017, 24.

"beds" that individuals must consider if they fit into, rather than vice versa. This limits the discourse around building innovative and responsive supported housing options.

Recommendations for Improving Understanding and Building a Solid Foundation For Supported Housing System Decisions:

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.

3.0 Strengthening Existing Models and Building New Models: Individualized and Shared Supported Housing

The DSP still represents the majority of funding for supported housing. Most of that flows to licensed homes operated by service providers observing the Licensed Homes for Special Care Act. There are other ways and means of accessing supported housing, and yet Licensed Homes appear to be the only housing model presented when navigating through the DSP system on government websites.

In fact, recent Flex-Independent and Flex-At Home funds have facilitated the creation of new models (including new unlicensed Small Option Homes), as well as arrangements around some individuals supported through Independent Living Supports. These show that it is possible to realize different types of housing and support structures, from minor to significant, in a variety of settings. However, these "Flex" and even many independent initiatives are not well-documented, evaluated or articulated in a publicly accessible way. This has resulted in a lack of transparency around how these innovative supported housing options are being developed and implemented, what possible challenges and opportunities exist, and may be curtailing the development of viable options for those who are interested in these types of arrangements, which could help to address the number of people on waitlists by connecting them to better fitted supported arrangements.

There are two problems with the current funding system. The first is the unmet need for utmost clarity around how Flex and other individualized funds are used. The second is the risk in streaming all dimensions of individualized funding from government through residential providers. If a provider is not regulated or does not have a person-centred plan and the capacity to support person-directed decision making, they may not be involving individuals or their families and supports in decision making about that person's larger daily and community living. This effectively flattens the individual' s existence to their life in the supported home, because all matters of funding—while presented as individualized—could be controlled or mediated by an organization that can subsume larger daily and community life into the operational needs of a house or institution.

Risk: Even though presented as individualized, many of the funds provided by DSP for supported housing are distributed through residential providers, and there are currently no checks in place to assure those funds are being informed by person-directed plans or decision making of the individual they are supporting.

Moreover, the slow rate at which existing spaces are opening, combined with the growing numbers, and the expectation from individuals for more flexible and community-based housing arrangements, have gridlocked the system. These conditions have created a supported housing crisis in Nova Scotia. Individuals and aging parents who are in desperate need of supported housing have begun to consider creating their own supported housing options.

One way to do this—which has been done elsewhere—begins by separating the funding and provision of daily assistance and support from the bricks and mortar of housing.[42] For example, several of the innovative models described in Ontario's recent evaluations of 18 supported housing options demonstrated that providing support services separate from residential services works well for some people.[43] While there are barriers and limitations associated with this approach, making it less than ideal for some, there may be a number of individuals and families who have the resources and energy and would prefer this option.

There are few funding sources that individuals and families may be able to draw from or should be aware of to make fully informed decisions. In some cases, families may find it possible to combine their own resources with the range of public and para-public (streams available through granting, crown or other non-directly government) streams. All of these are governed by rules that dictate where and when they can be used, as well as whether (and how) they can be combined.

No matter what the combination or arrangement of funding, there are risks. At the Supported Housing Ideas Summit, individuals, families, caregivers, and support professionals emphasized financial stress on families. As AutismNS also highlighted in its 2015 *Choosing Now* report, the unseen cost to families and caregivers in terms money spent and deferred income to support or care for a loved one is dramatic. It simply downloads a societal cost—of helping individuals live their best lives—to individual family units, essentially individualizing the responsibility for people with disabilities.

Yet, even in those instances where DCS is helping families connect to funding for supports and/or housing, the lack of support for those families around creating unlicensed arrangements is not fully understood. Because this is an emerging model in Nova Scotia, the evaluation of the models' implementation has not been developed for these arrangements. Specifically, as is explored elsewhere in this White Paper, unlicensed arrangements entail significant hidden operational and administrative costs that are often absorbed by families or caregivers out of necessity. The problems with this are more than the immediate hidden financial costs to the

[42] Kendrick, M. (2016). The Role of Agency and Systems Transformation in Supporting "One Person at a Time Lifestyles and Supports. TASH Connections. http://www.iimhl.com/files/docs/IIMHL-Updates/20170415c.pdf

[43] Ontario Developmental Services Housing Task Force "Final Report 2018. Generating Ideas and Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities."

family and the individual. It also creates the conditions where individuals with ASD or a developmental disability—and their caregivers—are often put in a conflicting position, receiving supports from or having supports overseen by a loved-one, who is simultaneously deeply invested as an advocate, while also having a right to increased independence apart from a family home. Much of this could be mitigated with an individualized rights-based approach (e.g. CRPD, Article 12), a Quality of Life Framework, and with measurable indicators that would apply to licenced and unlicensed service providers equally. This would provide an evaluative framework that could inform a well-planned process rather than continually reacting to crisis situations and allowing reactive practices to develop the system.[44]

3.1 Individualized Funding for Supported Housing

In Nova Scotia, there are instances where DSP's individualized funding is and can be used as an alternative to receiving direct supports through a DSP funded service or agency—so long as an individual meets specific criteria for funding. Also, an individual or a family member or a designated representative must have the capacity to direct and manage the funds, as well as, procure and manage the supports and services the funds may leverage—which if treated as an indefinite solution can create conditions outlined above. While some individuals and families would prefer residential supports provided by service providers, DSP individualized funding appears to be another stream of funding, that either can serve as a stopgap until residential supports become available or provide a solution with more flexibility in how services and supports are set up. This line of funding is the preferred by most in the autism community, because it allows for more flexible, person-centred, self-directed services so that, as one Summit participant noted, "I get to decide how funds are spent, move away from cookie-cutter "service"!"

Importantly, there is no additional administrative process needed around assessment, to move funds towards this individualized approach. The process for individualized funding is the same as the that used to determine service and support needs via a DSP-funded service provider. In both cases, approved funding is based on disability-related needs and available funding.

Based on data from DCS, the number of Nova Scotians receiving direct funding has grown over the last ten years from 2,390 to 2,920 for a net increase of 530 recipients. And the number of direct funding programs have increased from 3 to 6 (see Table 3 below). The program expansion appears to have separated children's funding from adult funding, but based on the publicly available information and figures, it is impossible to determine any specifics. Because DCS only recently transferred adult recipients out of the Direct Family Support (Children and Adults) program into the Flex Individualized Funding programs, it is difficult to be certain if this program has increased or decreased. **However, in the years prior to this shift, the number of**

[44] Autism Nova Scotia. *Choosing Now*; Claes C, Van Hove G, Vandevelde S, van Loon J, Schalock R. The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Res Dev Disabil*. 2012;33(1):96-103. http://linkinghub.elsevier.com/retrieve/pii/S0891422211003271. Accessed August 19, 2018.

clients in the Direct Family Support program for children and adults consistently fluctuated with a net increase in the program of 38 participants over three years (between 2012/13 and 2016/2017).[45] This was also the period when the provincial government had committed to investing and implementing the Roadmap report. T **the minimal growth in participants supported over the defined time period suggests a lack of substantial investment in this program d.**

Table 3: Nova Scotia Disability Support Program Direct Funding Recipients, 2006/07 Compared to 2016/17

Programs	# of Recipients 2012/13	# of Recipients 2016/17	Change +/-
Alternative Family Support/Associate Families	203	160	- 43
Independent Living Support/Supervised Apartments	677	741	+ 64
Direct Family Support (Children & Adults)*	1,959	665	- 1,294
Enhanced Family Support (Children)*	41	44	+ 3
Flex Individualized Funding – Independence*		1,301	+ 1,301
Flex Individualized Funding – In-Home*		7	+ 7
Totals	**2,880**	**2,918**	**+ 38**

*The Direct Family Support Program began in 2005. Flex Funding replaced Direct Family Support for Adult program in 2016.

The data available for the DSP direct funding programs, in particular the Flex program, raises more questions than it answers. For example, how much individualized funding is being provided based on the eligibility criteria, are the funds allocated for and actually being spent on supported housing, what kinds of supports are and are not covered, are some recipients receiving funding from more than one program, are the programs being combined and how, and how is the program being distributed across Nova Scotia in a way that all care coordinators or case workers understand the scope and capacity of the funding? Because the Flex program has not been well-articulated, it is not known how it is being applied or whether the outcomes are being achieved. The effect of this is unnecessary confusion and stress for individuals and families as well as a lack of transparency and accountability for the system as a whole.

> Risk: There is a lack of information and transparency around what Flex funding streams are, and what they cover, creating confusion among many self-advocates, families, professionals, and other key support providers about how and when to try and access these funds.

[45] Specifically, DCS reported 1895 recipients in 2009/10, increasing the program to 2,035 in 2010/11 (+140), decreasing to 2,015 in 2011/12 (-20), decreasing to 1,959 in 2012/13 (decreasing by 56 of which 41 moved to the Enhanced Family Support program), decreasing to 1,918 in 2013/14 (-41) and increasing to 2051 in 2014/15 (+133), and increasing again to 2073 in 2015/16 (+22).

This connects into a broader piece of feedback that emerged from multiple voices at the Housing Summit. Specifically, it is apparent that Nova Scotians are unclear about what is available to them for funding and supports and how to access it. As one Summit participant put it, "To get funding you have to know where it is and how to access it." In some cases, families may find it impossible to access and navigate what is an increasingly complex funding landscape and policies.

Moreover, the lack of clarity around the funding system has essentially created the conditions where DCS's care coordinators and frontline staff are forced to act as, at best, navigators, and at worst, gatekeepers. In either case, the ability of an individual or family to access supports is often disproportionately dependent on their care coordinator or case worker's literacy of the system funding and how to best utilize and access it.

This is a particularly problematic point because systems that are difficult to access or navigate because of unclear criteria are to likely magnify and perpetuate inequities—creating outcomes where those with time, money or social connections are more able to effectively navigate the system and garner resources than those without. In a similar vein, families may also combine their own resources with public resources to create supported living options that are not available to the majority of individuals and families. Importantly, there are very few cases in the current system where families or kinship networks are sustaining the housing needs of those with 24-hour care needs through private funds alone.

Of course, the flexibility to build supported housing arrangements around self-administered supports is important. At this time, it is not clear how families and advocates of individuals are involved and to what extent or how what their supported housing arrangements are designed and sustained. Based on information available through DCS, 1,301 program recipients are receiving funding to create their own support options in one form or another. Many individuals and families embrace this program and prefer it over other supported housing models. However, the extent to which capacity exists to develop and sustain the models, which are not well documented to begin with, is a significant unanswered question, given the intense interest in these models. Moreover, equity in access must be considered when evaluating the success of individualized funding as a system.

3.2 Individualized Supported Housing Models

A Massachusetts housing think tank recently catalogued the variants of scattered-site housing options (see section 2.2.1), all of which would fulfill the desire to move away from congregate housing models. Like in Nova Scotia, in Massachusetts these are less utilized and often not well outlined—usually because they are reliant on blending private and/or government and other funding streams. The following is borrowed from and elaborates on those structures concisely outlined in the Massachusetts Think Tank's work:[46]

[46] http://mahousingthinktank.org/defining-the-need/

- **The family home**: a family member provides support, or support comes in periodically.
- **The family as landlord**: the individual lives in an attached unit, with support that comes in periodically.
- **The family as landlord (with live-in support)**: the individual lives in an attached unit, with live-in support.
- **Live-in support**: the individual lives in a separate unit, with live-in support. The unit may be owned or rented by the individual, the family, or the support provider.
- **Assisted living or subsidized supported housing**: individuals may live in an assisted living facility or subsidized housing, with support that comes in periodically; this loans itself to the Independent Living Program stream of DSP funding.
- **Community mixed-purpose housing stock**: an individual lives in an apartment or home in the community, with support that comes in periodically.
    - This can take the form of general stock that is renovated or locally purpose-built, renovated affordable housing.
- **A small option home**: a number of people live in a small group residence, with support provided by workers. The home may be owned by individuals, families, independent incorporated entities, an agency, or a third-party landlord. The spaces are generally rented.
- **Purpose-built or renovated small-options with independent boards**: Purpose-established, with boards comprised of family and kinship network with a blend of professionals, overseeing operations of professionally staffed small option homes.[47]

There are examples of many of these already throughout Nova Scotia—though many Nova Scotians would struggle to connect to these models. Most recently, as part of the eight new houses announced in 2015, DCS has funded at least one group of families to develop arrangements similar to the last option, combining multiple benefit streams with Flex-independence funding to three individuals. This creates an independently incorporated, unlicensed, small option home, that is operated and governed by the families who administer supports and rent to the individuals. The bricks and mortar are either existing housing, or purpose-built housing. This arrangement may be appealing for two reasons. First, it creates, on appearance, an individualized housing arrangement that is created and mediated by an individual and their family or close kin/carers. Second, it helps keep costs to DSP and other sources low, by relying on the informal work and contributions of those support networks to operate and staff the house.

But family-governed models are also a delicate process, that require a high level of governance and support in their construction. It is not clear if the current landscape, which does not insist on a separation of the provision of housing and supports, means that these family-governed sites are not always built with an expectation, or oversight and governance, that assures an arrangement is rights-based, person-directed, and considering the broad social inclusion of residents. Family-governed models likely have a place in the landscape moving forward, but it is not clear to what extent they represent a generalizable solution, for several important reasons:

[47] http://mahousingthinktank.org/defining-the-need/

1. The level of the financial and in-kind contributions of families that run unlicensed small option homes is unknown—obscuring their true operational costs.
2. There is no packaged/manualized "model" for structuring, incorporation, supervision and operations, and it is likely, due to limited funding availability under this model, that these families are reliant on a level of social/familial capital and capacity that would pose significant challenges for most.
3. Very little is known or written about the successes or struggles of these arrangements, and because many of the operations and costs of the houses are actually sustained through the efforts of loved ones, many of these arrangements will likely experience sustainability issues in the mid to long-term.
4. While this model may cost the system relatively less than a supported arrangement delivered by an established service provider, it is very likely that that savings are being achieved at the expense of significant inefficiencies or downloaded in the operations of the model—particularly around core administrative dimensions such as book-keeping, human resources (including hiring, training and professional development, scheduling), payroll, and day-to-day management of staff.
5. And finally, while loved ones or caregivers are an important part of the operations of this model, the lack of formality, the lack of an evaluative system or lens (and specifically a Quality of Life lens) to both examine and guide them opens up individuals and families to dynamics that make it difficult for individuals to develop increased autonomy. Simply put this model ought to exist and may provide a promising emergent mode. But without some evaluative lens, and clear governance structures on which to build such a model, the sustainability and adherence to person-directed decision making in these arrangements are suspect. Moreover, because of the necessary involvement of family capital, this arrangement may contribute to inequities in access and use of supports, funding and resources.

The risks and unaddressed concerns that emerge with this model are not unique. In fact, while this is a more recent model, other models such as independent living, supported care in ones' family-home, and small community-based options all share a lack of accountability around assuring that the supports that are being delivered to an individual are indeed the most appropriate and informed by the desires and goals of the individual they are meant to support. Thus, this is not a model issue, this is a system issue, and any innovation in a system without an evaluative expectation that holds structures to account for their ability to respect the principles of person-directed decisions and planning will fall into the same traps due to a lack of accountability and insight.

RISK: There is currently little available in the way of evaluation or even awareness of the models of support and housing that are used in Nova Scotia. This means individuals and families struggle to make informed decisions about best fits for housing and supports and could push many people to arrangements that end up doing harm to the quality of life and rights of the individual, and costing the system more once it responds to the consequences of such mis fitted arrangements.

3.2.1 Unifying Resources to Enhance Individualized Options

If demand and desires are indeed pointing the way to increasing numbers of people accessing alternatives to congregate sites, the system will move toward increasingly dispersed models. This will effectively challenge models that see the arrangement of staff and skills as fixed to a specific building. It will also mean that supports and brick-and-mortar housing will become increasingly separated, making it even more important that a support service structure exists to help manage administration, implementation of person-directed plans, staffing, training, and supervision.

> Risk: Training and flexibility of staffing and training for staff, and standards of training already is, and will increasingly become, an issue for dispersed and congregate models, especially for those with complex support needs.

Most arrangements will still likely draw from DSP or DHW funding, and some individuals may draw from the housing allowances available through ESIA. It is important to note that there are other funding sources available that can help individuals and families tap into one of the blended models outlined above. We have listed these in "Appendix E: Disability and Housing Funding Resources." Overall, there must be an increased awareness of how various funds across multiple levels of government, can interact and how those can be connected to private dollars (from families, housing cooperatives, developers, and other parties).

> Risk: There are no comprehensive information resources or unified funding resources for individuals and families, or caregivers looking to explore funding options and associated supported housing models.

> Risk: Because of the growing demand for more flexible, scattered supported housing arrangements (both around the bricks-and-mortars and support infrastructure), administration of supports will become a challenge. New small option homes, independent living arrangements and other smaller-scale adaptations, particularly if they are run and operated by small groups or families, will struggle to consistently hire and train staff and will struggle with other operational elements of running a supported home.

Lastly, and perhaps most importantly, the Nova Scotia government's limited investment in individualized funding programs and the number of residential options over the last thirty years has created a bottleneck of long waitlists for DSP residential spaces and options. **This lack of investment, and the lack of a person-directed and Quality of Life Framework, is possibly the most fundamental barrier to prosperity and fuller inclusion in society and community. A system that is perpetually starved of financial means will create models that serve that scarcity rather than the rights and needs of individuals.**

Recommendations for 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.

3.3 Barriers Preventing Access to Supported Housing

In order for Nova Scotians to access or develop their own individualized supported housing option, there are several barriers to basic access that must be highlighted and removed. These barriers constrain the current state of the system, as well as the ability to understand how to move through that system or to imagine what is possible as a supported housing arrangement. This is not an exhaustive list of all barriers, and we will rely on the Nova Scotians providing feedback to develop a more robust list with related recommendations in the final draft of this report and in developing solutions in the future.

While discussion of barriers often immediately goes to the admittedly significant issue of the lack of availability of funded spaces, this section tries to break that compounded problem into its smaller elements, outlining barriers as risks and accompanying recommendations that might meet the wishes of an individual and families need for more options in their efforts to live in their preferred communities. Barriers to accessing the supported housing system was a theme that ran throughout the April IDEAS: Supported Housing Summit. There, participants from multiple perspectives voiced a desire for a fuller understanding of the supported housing system and how to engage with it, and emerging best practices or even basic models that could help shape conversations about options, for a policy that helps achieve supported housing ends, rather than acting as a barrier to their development.

3.3.1 Barrier 1 | Lack of Awareness

Many individuals and families lack the information and understanding on the process involved to inquire, about, explore and secure supported housing. As this paper has already outlined, there are several resources for preparing and planning that are not immediately available or known, particularly in the Nova Scotia context. This means it is hard for those who are approaching adulthood and their families to know how to start the conversation, and where to reach for resources that align what models are available for supported housing, what supports may look like, what funding is available, service structures that might be able to provide supports in various areas of life. In the ASD/DD community, for example, families are frequently unaware of even the existence of a Disability Support Program, unless they experience a crisis. They are often not directed to social services for persons with disabilities for supported housing services by health care providers or educators before graduation from high school. Additionally, families and individuals are frequently unaware of the need to plan well in advance for supported housing

or have no clear way to engage in that process. At the same time, many are unaware of person-directed or even person-centred planning facilitation as it is not easily or broadly available.

This creates a system with many entry points that often confuses or over-determines supported housing pathways, options, and outcomes. For example, some are entirely reliant on system-savvy social, health, or housing service providers or on word of mouth from other families and individuals, such that social inequities get baked into the accessibility of the system.

> Risk: There is a critical lack of awareness of the options, resources and limitations—to identify and steer individuals and families to available funding and options. The current patchwork of resources limits awareness of the building blocks of supported housing.

More should be done to explicitly provide information about supported housing arrangements and funding of any type and to increase compliance with the development and regular updating of person-directed plans that are connected to support plans.

3.3.2 Barrier 2 | Equitable Affordability

The affordability gap is growing for not only families supporting those with many needs, but those with a disability who are not in a family home. The 2018 *Building Poverty Solutions* report noted that 46.4% of people with a disability make under $20,000 a year, and 31.4% make under $40,000 in Nova Scotia.[48] Importantly, these numbers are for all disabilities and illnesses that disable, and which would impact the capacity for daily living activities. They are underestimations of the intersection between poverty and disability because they do not cover people living in congregate or other specialized supported housing arrangements.[49]

The unemployment and underemployment data from other countries suggest that the vast majority of individuals with ASD or DD, particularly those who have recently left or are leaving high school, probably cannot afford a home of their own.[50] For example, studies show that employment among people with ASD or DD, particularly younger people, sits between 10 and

[48]This United Way Halifax, *Building poverty solutions: Ideas for Action Halifax Regional Municipality*, Pp. 20-21 https://www.halifax.ca/sites/default/files/documents/city-hall/standing-committees/180326cped1031.pdf

[49] There is an over-reliance on the Canadian Disability Survey numbers for data on the number of people with a disability who are low-income and in core-housing need. This survey is built on a labour-market focus that through sampling bias following from the pool gathered in the long-form census, precludes those who are living in congregate arrangements (from group homes to nursing homes) and only tracks the income, earnings and needs of those either still living in a family home, and *not* living in a congregate arrangement. It also precludes many persons who may not identify with the axis of barriers to daily living that the long-form census asks about. This distorts our understanding of the depth and breadth of the affordability barrier for individuals both with significant support needs and for those with less significant support needs. Also see CMHC, Research Insight: Housing Conditions of Persons with Disabilities. May 2018.
https://eppdscrmssa01.blob.core.windows.net/cmhcprodcontainer/sf/project/cmhc/pubsandreports/research-insights/research-insight-housing-conditions-persons-disabilities

[50] National Center on Special Education Research, Institute of Education Sciences. (2011). The post-high school of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2), Washington, DC: US. Department of Education.

25 percent in similar countries to ours (i.e., United States or UK).[51] Even those who are employed tend to "earn less than the national minimum hourly wage, endure extended periods of joblessness and frequently shuffle between positions, further diminishing their prospects."[52] Instead, they are relying on parents, family, social services such as Employment Support Income Assistance (ESIA) or, wherever barriers in assessment do not prevent it, the Disability Support Program (DSP; see Funding Barriers for more on this). For people with ASD/DD, it is essential that support and housing are considered together because, without adequate support, people will not be able to live well in their homes.

At a minimum, Nova Scotia should follow Ontario's lead (as well as jurisdictions across North America such as California) and make funds available for Person-directed Planning development as a consistent funding line and expectation for the system .[53] The province should also explore the possibility of moving toward models that exist in other jurisdictions, where funds for supported housing are only disbursed to any provider (licenced or unlicensed) if there is compliance with the creation and ongoing updating of a person-directed plan, which meets particular standards of practice, for all individuals.

3.3.3 Barrier 3 | Equitable Availability and Accessibility

While there is a wide consensus that there is an affordable and accessible housing shortage in Canada, and in Nova Scotia, that shortage is even more acute for persons with disabilities requiring supports. It is concerning that such a significant portion of the population of persons with developmental disabilities is so markedly and consistently below the low income and poverty lines but often require built spaces that can accommodate additional needs. The limitations are not just the lack of awareness and lack of *affordable* options; it is also the lack of accessible options because the lack of support or assistance is not always promoted as an accessibility barrier. There are, simply put, few *actual* options for those who need supported housing outside of the current 24/7 residential service models—particularly in rural areas, areas with limited affordable housing, and a decreasing number of people willing to work as support personnel.

> Risk: There is a growing shortage of affordable and accessible housing, which is increasing the cost of individualized accommodations at a system level by aggravating the situation of individuals with the most acute health and social services support needs. Coupled with a lack of flexible support and housing options, it is very likely that while some can receive inadequate supports, others are pushed into residential arrangements that actually exceed their support needs.

[51] National Center on Special Education Research, Institute of Education Sciences. (2011). The post-high school of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2), Washington, DC: US. Department of Education.

[52] Dudley, C., Nicholas, D. B., & Zwicker, J. (2015). What do we know about improving employment outcomes for individuals with Autism Spectrum Disorder?. *SPP Research Paper*, *8*(32).

[53] For examples of how California is making Person Centred Planning integral to funding for support services providers see: https://www.dds.ca.gov/SLS/docs/DevelopingSupportedLivingServices.pdf ; https://www.nlacrc.org/Home/ShowDocument?id=213.
Ontario's arrangement for funding person-centred planning can be seen here: https://www.mcss.gov.on.ca/en/mcss/programs/developmental/servicesupport/person_directed_planning.aspx

The provincial housing agency (Housing Nova Scotia) has programs such as the Disabled Residential Rehabilitation Assistance Program and the Access-A-Home Program—as well as New Construction Seed Funding through Canada Mortgage and Housing Corporation (CMHC)—that can help defray the cost of built accommodations required by those who can access affordable housing. There are also rent supplements available through Housing Nova Scotia, via the Employment Support and Income Assistance (ESIA) streams of government funding. However, the pathway and guided process to connect these brick-and-mortar arrangements to the supports for people with disabilities is unclear and hard to navigate. In other words, an individual or family looking for supported housing solutions might confront a long menu of options (if they can find it), but the task of selecting and combining them in ways that meet individual needs is overwhelming by design.

3.3.4 Barrier 4 | System-Centered vs System-Facilitated Person-directed/centred Supported Housing

System-centred thinking constrains what can be said and done about supported living. It undermines and stifles innovation. This is probably most relevant in the growing emphasis on and development of small option housing, which is fast emerging as the dominant model of supported housing in Nova Scotia and elsewhere. There is ample evidence supporting this small-scale form of congregate housing, and there are certainly benefits around shared supports. One of the demonstrated areas of supported housing growth funded through DCS—while small—is small option homes. But the growth has not come close to meeting demand.

Indeed, the largest documented waitlist for residential options is specifically for small option homes. The Province also notes that the formal waitlist is likely shorter than the total of those who *actually* want to live in a small option home because many individuals or families are discouraged by the length of the waitlist and are not be applying. But the response to pressure to grow more is typically that the investment is too expensive for the system. There does not even appear to be a desire to know more about the demand for small options homes. What are the characteristics of people waiting? What specifically is attractive to them about small option homes? How might the system efficiently and *systematically* meet the demand, rather than haphazardly growing wherever it is convenient or an emergency measure? In order to work to understand the desires of the community, and to develop a plan to realize them, there needs to be a shift from seeing the system as something that constrains possibilities to seeing the system as a way to facilitate better Quality of Life for individuals.

> Risk: Because the supported housing landscape has been so starved of resources, and access to supported housing largely crises-driven, there has been little effort made to capture and articulate the general and appropriately varied desires and needs of the DD/ASD community. Because the constraints of the system come first, the desires of individuals never get the serious attention they warrant.

3.3.5 Barrier 5 | Lack of Collaboration Between Health, Social, Justice, and Community-based Supports

There are a significant number of persons with ASD and other developmental disabilities who have moderate, high, or intensive supports needs due to co-occurring conditions and related health or environmental issues. These conditions often require that individuals reach beyond what is conventionally understood as their supported housing scheme, to draw from resources in Health, Mental Health, Justice, and even municipal areas such as recreation. One example is those who need mental health supports. Individuals living in a residential arrangement such as a group or small option home,may experience emergent health or mental health issues that need attention beyond the current disability supports provided via supported housing. Many individuals, their families, and service providers will struggle to know how and when to request such supports. This can cause otherwise durable housing arrangements to deteriorate and more complex individual and group issues to emerge, eroding relationships and well-being. More must be done by the government, in collaboration with other parties, to assure that the supported housing landscape is not being treated as a fix-all or substitute for needed health and justice interventions.

> Risk: Supported housing, no matter what the arrangement, is only one sphere of an individual's life. There is a significant risk to individuals' relationships, well-being, and living arrangements, when support providers are not integrated within wraparound services. A system built in this way effectively marginalizes individuals within a supported housing arrangement, making it difficult for them to get the treatment they need and realize their goals.

There are also many individuals who are not accessing DSP at all, who remain unconnected to disability support services across the gamut, but continue to rely on services in other support systems at a disproportionate rate because of lack of housing supports their disability. For example, many autistic individuals who do not have an intellectual disability (which would make them a candidate for DSP) still struggle with activities of daily living, and would still benefit from accessing minor supports through an individualized supported housing system. In fact, starting with housing—instead of with all the additional supports--could even help regulate the conditions that often aggravate behavioural, physical health, and mental health conditions in the first place.

alone lacks the capacity to prevent or address any of these conditions and as such, are forced to go to other government departments. Often this action occurs when the problem becomes an emergency and the situation has reached a crisis point (e.g., injury, abuse, or media attention). So, a situation that could have been easily addressed at an earlier juncture through outreach and home-based health services now requires a significant system response of expertise and wastes our finite resources, as it possibly involves those who are not used to working together with different mandates and expected to adhere to often disparate policies (e.g., Department of Community Services, Department of Health and Wellness, and Department of Justice).

> Risk: There is a very real risk of an undue and increasing reliance on long-term care facilities such as "in-patient facilities" or exclusion of individuals that need supported housing but

have behavioural needs or significant physical barriers that exceed the current capacity of what can be provided in supported housing. If residential services providers are adequately resourced to support individuals and have the necessary skill sets (i.e., notes these skills are typically those outside of the currently required competencies by DCS), the likelihood of individuals being moved to restrictive environments is reduced and with the risk of individuals losing their supported living arrangement.

Risk: Persons requiring less intense supports are at particular risk of isolation or struggle to move between siloed and complex service structures. This will, ironically, often aggravate issues around mental health. Many are dependent on family and kin to help them access supports for the host of issues they may be dealing with. The result is that persons with ASD and other disabilities often lurch between support and service systems, degrading trust in the system and often aggravating poor health and mental health conditions, pushing individuals deeper into or closer to crisis.

3.3.6 Barrier 6 | Dealing with Homelessness and Hospitalization

This latter situation helps explain the significant over-representation of people with ASD who are homeless or hospitalized.[54] We are only beginning to understand the impact that homelessness has on individuals with ASD and DD. Its relationship to hospitalization, its relationship to access of disability appropriate supports, and particularly its relationship with supported housing. One recent British study found that autistic traits are over-represented (as many as 1:10) among the homeless, and that autistic homeless people show a distinct pattern of characteristics and needs.[55] There is an already an emerging body of literature on the vulnerability and enhanced trauma of homelessness among the developmental disability community.[56] And this extends out to most disabilities, particularly where aging family or kinship networks are caring for adults because of limited access to services, except in crisis situations. In these situations, even the smallest change in a family member or kinship tie can throw an individual into housing and supports crisis or homelessness.

Again, as noted above, these situations often require a collaborative and wraparound system response involving the Departments of Community Services, Health and Wellness, and/or Justice. In the current system, these situations are managed on a case-by-case basis necessitating the cobbling together of disparate services rather than accessing an existing and established wraparound service. Often the resources required to create and recreate wraparound services and supports are hidden yet they represent an onerous cost to the system. But because these resources are squeezed out of multiple budgets draining professionals of their capacity and individuals'

[54] Churchard *et. al. "*The prevalence of autistic traits in a homeless population," *Autism;* April, 2018.
[55] Churchard *et. al. "*The prevalence of autistic traits in a homeless population," *Autism;* April, 2018.
[56] https://www.homelesshub.ca/resource/looking-poverty-income-sources-poor-people-disabilities-canada

QOL (both of which go unmonitored) it continues to be an ongoing and pressing issue and remains unresolved.

Taken together, without an established wraparound service, there is a clear over-representation of individuals in poverty, and at-risk or already in a homeless situation. Front-line homelessness workers often struggle to connect individuals to supports and services or solutions that can adequately support an individual with a disability. Evidence indicates that as many as 80-90% of people with ASD are unemployed or not in the labour force. Of the 10-20% percent of individuals with ASD who are employed, many are working minimum or sub-minimum wage jobs. This means that as many as 90 percent of people with ASD are either at risk of a housing crisis or have unmet housing and support needs in one form or another.

3.3.7 Barrier 7 | Improving Training for Service Providers

No matter what the alignment of the housing system—be it one that promotes congregate residential services that blend dollars for housing and supports, or a more individualized support system, one of the major pieces of feedback we have received throughout consultations is the need to build knowledge and professional capacity through training for support workers. Service providers' expertise often varies, with pockets of excellence, and significant gaps in capacity in other areas. Structurally, the capacity of supports in the system is limited by two major challenges.

First, it cannot be ignored that the low pay and often very challenging support situations that professionals must enter, has created serious barriers in recruitment, retention and maintaining corporate knowledge. There is a real risk that training in such a churning labour market puts organizations, big and small, in a vulnerable position when staff leave with their built skills. Second, the current standards of care and related core competencies keep expectations low, and far away from the principles of person-centred and rights-based approaches. While the core competencies rightly focus primarily on safety and protection, there is a significant lack of focus and expectation around having of building professional skills around supports—particularly behavioural supports, and around person-directed decision making.[57] While existing standards meet a minimum standard of care, they do not ensure that a residential service provider or even a distinct service provider will employ staff with skills to support the implementation of person-directed plans, which raises concerns that the system is inadvertently promoting custodial practices (caring for) rather than being with and supporting individuals in a way that promotes agency and quality of life, building active supports tailored to the individual.

Recommendations for Strengthening Supports and Housing to Overcome Barriers

Recommendations for Government

[57] The seven "core competencies" include: fire and life safety; basic principles and practices of personal care; medication; individual program planning; positive principles and practices of non-aversive behaviour change; crisis intervention, and standard first aid. For the most part, each of these is taught over a half day.
https://novascotia.ca/coms/disabilities/documents/Disability_Support_Program_Policies.pdf

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.

Recommendations for the 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 disbursal 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, 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, self-advocates, 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.[43])

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.

4.0 Conclusion: Moving Forward Together to Build to Better

Nova Scotians' desires and expectations, as well as our understanding of the most effective arrangements for supports and housing, are shifting. The numbers of people waiting for housing options, the local lived experience, and official documents going back for over a decade all show this shift in thinking —likely because of the Nova Scotia government's decision to deinstitutionalize children in the early 1990's, which opened eyes to the potential of people with disabilities and the need for fuller participation is society. This shift from being raised in institutions to being raised with parents, brothers, and sisters, attending neighbourhood schools, and taking part in ordinary community life has been a catalyst for encouraging person-directed lives, as well as inspiring the evolution of inclusive models. All of which has forced the system to evolve and create more familiar independence-building options across Nova Scotia.

Most importantly, this also means that people expect better. Fewer people, particularly among millennials and their families, are either content or wish to live in large residential and even group homes; and so, the demand for individualized, small, person-directed homes as well as independent living arrangements is far outpacing supply, and slowing the ability to shift the system in new directions.

This paper has clearly outlined that system change cannot and should not be accomplished by one entity. It is not practical or efficient because it does not build the capacity needed for long-term sustainable practices and actions. Moving to the more person-centred, quality of life, fuller citizenship building system this paper has tried to outline can only be accomplished through collaboration between governmental departments, community-based organizations, individuals and their families, and requires administrative support to help coordinate efforts, that will through action advance policy, build broader public awareness and acceptance, and mobilize funding in an efficient and just way.

The ingredients and systems that can breed successful collaborative initiatives have been well-documented and studied. However, it should be reiterated that how these are developed and the direction such initiatives take, must necessarily be driven by the principles of the collective of

people and organizations in this landscape.[58] A collaborative group could address the immediate risks and issues identified in this report. It could focus on the recommendations, addressing the complex issues and systemic barriers, while moving towards improved outcomes for individuals with ASD/DD and enhancing supported housing capacity in Nova Scotia. The development of a formal collaborative approach could provide a unique opportunity to harness the investment, innovation, and capacity of Nova Scotians. It could enable government, community members, and service leaders to work together to address the barriers that prevent Nova Scotians with ASD/DD from participating in the full experience of living quality lives in the community.

4.1 Building to Better, Together

Currently, the demand for individualized options affects all who provide supported living arrangements. It affects those who are not established service providers but may want to build supported housing options. It forces existing service providers, with viable models for development and operations, to resist or embrace new ways of thinking and alternative models. It also forces those without an existing model to individually face significant challenges as they attempt to shift the system to a more person-directed and responsive entity.

In this paper, we have reviewed the important and necessary challenges associated with individualized approaches. And importantly, we have found that the high level of planning, operational adaptations, and development can and is being done elsewhere in Canada (see Ontario's recently released Developmental Services Housing Task Force Report[59]). While this can be a significant challenge if arrangements are being developed by, for example, families and individuals (perhaps with support from developers or other stakeholders), because the pathways are not clearly laid out and the level of ongoing project management and operational demands to assure the proper development are not readily available, it can be done with the right guidance and investment. However, those developing and running a supported living arrangement will often underestimate what is required to do so. Moving forward, we must make the process transparent and ensure the right supports are in place so that service providers, volunteers, and family members do not exceed their resources.

Alongside the current lack of supported housing options, and the desperation of individuals and families to access supported housing, there is an opportunity to build capacity and channel the human, social, and financial capital of those wishing to develop individualized arrangements. On the other hand, it is unrealistic, at best, and potentially risky, at worse, to assume that families or support networks will absorb all of the responsibility for operating various supported living arrangements longer-term, yet these arrangements are desperately needed. However, if we fail to bring these stakeholders together and continue to operate in silos, it actually creates waste by

[58]"Channeling Change: Making Collective Impact Work." Fay Hanley Brown, John Kania, and Mark Kramer. Stanford Social Innovation Review. January 26, 2012. Available from: https://ssir.org/articles/entry/channeling_change_making_collective_impact_work

[59] Ontario Developmental Services Housing Task Force "Final Report 2018. Generating Ideas and Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities."

failing to create economies of scale that could come with a "batched" delivery of everything from hiring, training, and staffing to payment of rent, maintenance, accounting, and planning.

This connects to a larger, recurrent theme that has emerged throughout this report and at the Housing Summit event: specifically, the need for clearer direction on how to access and learn about current residential options, and how to develop various models of supported housing. Including support for all stakeholders in how to navigate to and connect with other resources and players looking to build supported housing systems.

The lack of coordination affects individuals, families, professionals such as tradespeople, developers and prospective financiers. Even though there is a widely acknowledged affordable housing shortage (especially in the area of accessible or purpose-built housing to meet accommodation needs) and an under-resourcing of supports, for those interested in trying to purpose-develop housing, the process of planning for the development, support plans, operational considerations, and how to assure the long term viability of a supported living arrangements are questions each person or group is left to re-discover in isolation from those that came before them or currently on the same track. This lack of a coordinated point of information and direction represents a lost opportunity that could help drive additional resources into a system that is unnecessarily and perhaps overly reliant on DSP and public dollars, but which could easily benefit from the funds and skills that could be harnessed through collaborative projects or initiatives.

> Final Risk: There is no clear point of entry where the individuals, families, developers and other stakeholders interested in addressing the shortage of supported housing (both the arrangements of supports and the actual housing infrastructure) through their local initiatives, can receive support and guidance on the building blocks that should be planned for in creating any supported housing arrangement, particularly a purpose-built one.

Building system capacity for developing more supported options in various forms would complement and scaffold the capacity of those individuals and families who play the role of planners, coordinators and project managers. Capitalizing on the strengths of Nova Scotians with ASD/DD and their families to build a better future for themselves inspires a call to action that no one should ignore.

Appendices

Appendix A: Terminology and Definitions

Autism spectrum disorder involves persistent deficits in social communication (i.e., social-emotional reciprocity, nonverbal communicative behaviours used for social interaction, and developing, maintaining, and understanding relationships). Restricted, repetitive patterns of behavior, interests, or activities (i.e., stereotyped or repetitive motor movements, use of objects, or speech, insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal-nonverbal behavior, highly restricted, fixated interests, and hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment) are also common. Intellectual disabilities involve intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Intellectual functioning is reasoning, learning, and solving problems; adaptive behaviour is conceptual, social, and practical skills in everyday life. Intellectual disabilities are under the category of NDs and include global developmental delay, and unspecified intellectual disability.[1]

Developmental disabilities are a group of conditions involving impairment in physical, learning, language, or behaviour areas of growth and development (e.g., Down syndrome, cerebral palsy, autism spectrum disorder, or muscular dystrophy).[1]

Throughout this document you will see the terms ASD and DD and how they apply to individuals, referenced in a number of ways. Language within the disability community is evolving as more is understood about how diagnoses, labels, and disabling environments impact individuals and the lives they lead. For example, Autism Nova Scotia represents a large and vibrant community — supporting individuals directly as well as providing supports for families and caregivers. The self-advocates who contribute to Autism Nova Scotia have varied preferences when it comes to how they would like to be identified. Some prefer identity-first language and wish to be called “Autistic”, while others would rather people use “person-first” language such as “on the Autism Spectrum” or “Individual with Autism”. One thing that we are very adamant about is that it is up to the individual themselves to determine how they wish to be identified. That is why you will notice we include different representations throughout this paper, in the hopes that our members can all relate, and see themselves within this report.

Supported Housing: any housing arrangement that combines a brick-and-mortar infrastructure with individualized, flexible support services for people with developmental disabilities. For persons with disabilities, supported housing is often a piece of a larger supported living infrastructure that helps them to build relationships and be active citizens in local communities.

Person-centred (or person-directed) planning: a series of approaches designed to help persons with disabilities plan for their future and supports. Importantly, the tools that comprise person-centred approaches are always structured in a way so that the planning is driven by and developed *with*, rather than *for*, the individual. They help a person think about what is important in their lives now and express their goals wishes and hopes for the future. Person-centred and

person-directed planning is the accepted international standard of planning for all aspects of life for individuals with disabilities.

Support: Support in the context of Autism or Developmental Disabilities is taken in this paper as referring to any assistance, adaptation or accommodation that allows a person to participate as live the best quality of life, through (for example) primary, secondary and post-secondary education; volunteer work; social activities and relationships; transportation; employment; celebrations; recreation and physical activity; entertainment; arts and cultural activities; consumption and shopping; and civic engagement (voting, advocacy, protest).

Wraparound System of Supports: In Wraparound systems of support, formal services, community resources, family and friends are joined in a collaborative, planned effort to help a person with a disability address their needs. The innovation of Wraparound systems is the integration of supports provided by, for example, paid caregivers, organizations, volunteers, friends and family, agencies, and so on, in the pursuit of goals set in a person-centred and directed plan. At the system level, Wraparound support systems depend on productive partnerships and collaborations amongst agencies and organizations (Debicki, WrapCanada, 2014).

Quality of Life: The World Health Organization (WHO) defines "Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."[163]

Appendix B: How many people have a diagnosis of ASD in Nova Scotia?[60]

The projected estimates of prevalence in the Table 1 must be interpreted with caution, particularly for age ranges below or above the population age range used by PHAC (i.e., 5 – 17 years-old in 2015). For example, the projected estimate of 618 children with ASD, 0 to 4 years-old, in NS is likely overreported because PHAC reports that in Canada only 33% of children are diagnosed by age four[5] so if this percentage also applies to NS then the actual estimate would be 204 children (i.e., 618*33%). PHAC also reports that less than 50% of children are diagnosed by age five, and 78% are diagnosed by age nine.[5] The reasons why the age of diagnosis varies can depend on many factors such as at what age parents and caregivers identify the signs of ASD, obtaining a referral for an assessment, availability of clinicians, and timely diagnostic services and waitlists. Another example is the projected ASD prevalence rates for people 40 to 64 years and 65 years and older for these too may be overreported or overreported. The life expectancy for people on the spectrum may be less than 65 years, and this would translate into much lower numbers than reported here.[19]

Focusing on the transition of youth and supporting adults with planning for their home environments and how they want to engage in their community. Based on the community AutismNS serves, it may be reasonable to use the projected prevalence rates for the age groups of 20 to 24 years, 25 to 29 years, and 30 to 39 years, 40 to 64 years, and 65 years and over, providing an estimate of 10,860 youth, adults, and seniors living on the spectrum in Nova Scotia. These estimates may be revisited and further extrapolated for more specific population planning as the strategic planning process unfolds.

[60] Hutchinson et. al. pp. 50-51.

Appendix C: Cumulative Incidence of Childhood and Adult Developmental Disorders among Nova Scotians, 2011[61]

Table 43: Ten-year cumulative incidence of childhood and adult development disorders among Nova Scotians (by DHA and gender) based on ICD-9/ICD-10 codes drawn from PHRU databases (number of cases, age adjusted rate per 100, and 95% confidence interval)

DHA	Gender	Cases	Age-Adjusted Rate	Lower 95% CI	Higher 95% CI
1	Female	578	0.26	0.24	0.28
	Male	1145	0.52	0.49	0.55
2	Female	354	0.14	0.12	0.15
	Male	778	0.31	0.29	0.33
3	Female	874	0.24	0.22	0.26
	Male	1479	0.43	0.41	0.45
4	Female	700	0.21	0.19	0.22
	Male	1508	0.43	0.40	0.45
5	Female	264	0.20	0.17	0.22
	Male	517	0.39	0.35	0.42
6	Female	297	0.15	0.13	0.16
	Male	600	0.30	0.28	0.33
7	Female	355	0.18	0.16	0.20
	Male	757	0.39	0.37	0.42
8	Female	959	0.18	0.17	0.19
	Male	2011	0.38	0.36	0.40
9	Female	5145	0.29	0.28	0.29
	Male	9269	0.53	0.52	0.54
Unknown	Female	410	0.31	0.28	0.34
	Male	736	0.60	0.56	0.64
Nova Scotia	Female	9936	0.24	0.23	0.24
	Male	18800	0.46	0.45	0.47

In lieu of Nova Scotia specific data, studies from other countries, including the United States, Germany and Australia (which have similar estimated prevalence rates and distributions) can help us get a sense of the likely picture of how many people with ASD might need supported housing. Studies show that employment among people with ASD, particularly younger people with ASD, sits between 10 and 25 percent. Importantly, one Canadian policy review noted that of those employed "most earn less than the national minimum hourly wage, endure extended periods of joblessness and frequently shuffle between positions, further diminishing their prospects. Poor employment outcomes result in lower quality of life and often lead to steep economic costs."[62] This not only points out the startling relationship between autism and poverty, in so doing it suggests that the vast majority of individuals with ASD, particularly those who have recently left or are leaving high school, are not likely to be able to afford housing of their own, relying instead on parents, family, social services such as Employment Support Income Assistance (ESIA) or, wherever barriers in assessment do not prevent it, the Disability Support Program (DSP; see Funding Barriers for more on assessment barriers).

[61] Asbridge, Mark; Pauley, Chris et. al. Dalhousie University, Department of Community and Health Epidemiology, September 2011

[62] Dudley, C. et. al. (2015) What do we know about improving employment outcomes for individuals with Autism Spectrum Disorder. The School of Public Policy. University of Calgary.

Appendix D: DSP Waitlist Information as of November 27, 2017

The following is a direct excerpt from DSP Waitlist Information (2017). It was submitted as Exhibit 45 in the Nova Scotia Human Rights Complaint.[63]

The waitlist for the Disability Support Program (DSP) includes:
1. applicants not receiving DSP support;
2. participants receiving DSP support but requesting/requiring a different program option or location;
3. applicant/participants wanting immediate placement;
4. applicant/participants wanting future placement.

As of November 27, 2017, there were 1490 individuals on the DSP waitlist.

Small Options

When reviewing the waitlist for placements, the first considerations are type of support option, Level of Support, Priority, and Date of Waitlist Submission. Once a short list is determined, the regional waitlist designate reviews additional information to ensure a match with the available support option.

As of November 27, 2017, 1028 of the 1490 individuals on the DSP waitlist were requesting Small Option as Option 1, 2, or 3.

Below is the breakdown of individuals seeking Small Options by Level of Support and Primary Diagnosis:

Level of Support	**Case Count**
1 - Minimal	84
2 - Moderate	333
3 - High	306
4 - Enriched	163
5 - Intense	142
Total	**1028**

Primary Diagnosis	**Case Count**
Intellectual Disability	633
Long Term Mental Illness	290
Other*	9
Physical Disability	96
Total	**1028**

* "Other" should not be listed as a primary diagnosis. This has been removed from the computer system as an option. It likely relates to acquired brain injury.

Central is the most commonly requested region. 458 individuals are requesting only Central region, with an additional 173 requesting Central in combination with other acceptable regions.

63 A link to the full document is posted on the Disability Rights Coalition of Nova Scotia: Independent human rights board of inquiry into Beth MacLean, Sheila Livingstone, Joseph Delaney and the Disability Rights Coalition of Nova Scotia v. Province of Nova Scotia website. https://www.disabilityrightscoalitionns.ca/a-selection-of-documents-from-the-human-rights-complaint/).

Appendix E: Supported Housing Planning, Support, and Funding Resources

Find in Appendices File under Op Director→Housing Think Tank→White Paper Appendices

Navigation for Adults with a Disability
http://www.planningnetwork.ca/en-ca/Resources/25084/P4P-Tip-Sheets-Download

Connectability
https://connectability.ca/2018/04/25/becoming-an-adult-transition-planning-for-youth-with-a-developmental-disability/

Understanding the DSO & individual housing options
https://slideplayer.com/slide/15972755/

Empowering Ability Workbook: Creating a Home for People with a Developmental Disability
This organization shares various useful resources through podcasts/blogs about all things related to individuals with an intellectual/developmental disability (including housing). ClickhereOpens in a new window to check out their website.
Furthermore, Empowering Ability created a workbook for individuals with an intellectual/developmental disability that want to create a home of their own, where they are able to have choice and control of their life. Click hereOpens in a new window to access their workbook.

'A Home that is Right for Me'

This document describes how to create an individualized residential model for people with a developmental disability. The guide outlines how to create a vision and plan for housing options, figuring out costs and funding sources, finding supporters and how to sustain the living environment overtime.

Tool for the Assessment of Levels of Knowledge: Home Alone

This assessment tool will help with the decision making process as people move towards their goal of independence. The tool is set up to look at a variety of different skills that are necessary for someone to be able to stay home safely. It should be noted that this tool is not exhaustive regarding potential risks. It looks at universal risks. There is a section in both the staff and person components of the tool that allows for discussion of idiosyncratic risks that a person may face.

STEPS To Independence

STEPS To Independence is a guidebook that provides an opportunity for individuals with an intellectual disability to determine how prepared they are for semi-independent living. It provides a holistic tool to prepare someone for semi-independent living by identifying current skills, determining skill areas for improvement (where more learning can happen) and next steps to focus on.

STEPS To Independence identifies current skills for semi-independent living and determines areas for improvement, using a holistic guide that provides a perspective on readiness. It helps to distinguish if more coaching and learning needs to happen in specific areas prior to the transition to semi-independent living taking place, and if someone is well on their way to semi-independent living. Click here Opens in a new window to access the document.

Posssible Funding Sources

https://dennispilkey.files.wordpress.com/2019/02/housing-and-housing-support-grants-and-programs.pdf