



MEETING THE HOUSING CHALLENGE

Understanding the Housing Needs and Desires of Autistic People in NS

by Karen Foster, Paula Hutchinson, Brian Foster and Tristan Kowal

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Nova Scotia has struggled to provide community-based, non-congregate, appropriate housing for disabled people¹ for more than three decades. Beginning with the intentional closure of many large-scale institutions in the 1990s and into the 2000s, successive provincial governments have acknowledged the need to move away from large-scale congregated, often custodial and highly medicalized spaces. This was part of a broader acknowledgement that such environments segregated disabled people from the rest of the population, in often dehumanizing and problematic custodial contexts that did not respect an individual's rights (Barken, 2011).

This acknowledgement led to a surge in the number of smaller 'group homes' in the 1990s until the mid-2000s, as the Nova Scotia government tried to fund new congregate arrangements at a smaller scale. But even these group homes often presented their own challenges in time. These were perhaps most concisely captured in what became known as the "Kendrick Report," a Review of Nova Scotia's Community Based Options, commissioned by the government of 2001. It noted that to move further away from institutions, governments needed to focus spending on *individualized* supports and modernize the options and system of housing and supports for persons with disabilities (Kendrick, 2001). Some saw the proliferation of small option housing (where 4 or fewer people with disabilities co-housed) as the route to a reformed disability housing landscape, although as Kendrick noted, small option living was not the same as individualized supports. In any event, most efforts for further development of housing ceased with what became known as "the moratorium," a government decision that largely quelled any new supported housing developments through most of the 2000s. The moratorium, unsurprisingly, triggered a surge and backlog in the number of people waiting for housing and services, as well as an actual decrease in the number of people served by the income supports and program streams that are funded under what is now called the Disability Support Program (*Road to Inclusion by 2023*, 2021).

¹ In this report, we use the terms "autistic" and "autistic people". There is a healthy debate within the autistic community about the preferred terminology. Among self-advocates both nationally and internationally, "autistic" and "autistic people" — the "identity-first" approach — is preferred and certainly increasing in popularity. For more information, see: <https://autisticadvocacy.org/about-asan/identity-first-language/>

In 2013/14, another government again committed to reducing its reliance on large, congregate living arrangements for people with disabilities, emphasizing the need for and shifting toward a person-centred, dispersed model of housing where disabled people live in typical housing or apartment arrangements, in neighbourhoods with everyone else, connected to person-centred supports that match their individual needs. Accepting the recommendations of a joint community-government taskforce's report, *Choice, Equality and Good Lives in Inclusive Communities* (generally referred to as the "Roadmap" within provincial discussions), the province pledged to make long-demanded changes to the disability housing landscape across Nova Scotia, alongside a number of other changes to how it delivers services and supports to disabled Nova Scotians of all ages, by 2023. Elections have ushered in new governing parties, but there has been tri-party consensus that the recommendations around housing outlined in the Roadmap and most recently affirmed by a Court of Appeals case in the province that individualized and non-institutionalized living is the appropriate and necessary direction for housing for persons with developmental disabilities. The most recent case established that the Province systemically discriminated against persons with disabilities by keeping people on years-long wait lists for necessary supports, institutionalizing some persons unnecessarily, or by requiring people with disabilities to move communities in order to receive support.²

Yet, in 2021, less than two years away from its self-imposed deadline, the province's progress on meeting the Roadmap's commitments is unimpressive. The Nova Scotia Disability Rights Coalition, taking stock of changes since 2013, found that "the number of persons residing in institutions [had] dropped by between 15% – 24% since the 2013/14 Roadmap commitment", but the creation of new spaces in communities, such as small options group homes, had failed to "match" the needs introduced by the gradual closure of institutions (*Road to Inclusion by 2023*, 2021, p. 4-5). The slow progress is affecting the lives of thousands of disabled Nova Scotians, their families, and the communities to which they contribute and belong. Those impacted by inappropriate and insufficient housing options and related supports comprise a diverse group, with physical and/or developmental disabilities, from a range of socioeconomic backgrounds. There is crucial work to be done by advocates, working in coalition with one another to advance this cross-disability challenge.

At the same time, it is also important to understand the unique housing needs, gaps, opportunities, and desires among disability groups. In this report, we present the results of a research study focused on the housing and support history, current situations, and desires and anticipated needs over the next five to ten years among autistic people in Nova Scotia who will require varying degrees of support to live in community. The study was conceived in response to Autism Nova Scotia's 2019 White Paper, *Building to Better*, which called for a greater investment of resources in efforts "to understand [...] the existing system and the people in it by quantifying unmet demand for supported housing and gathering data on desires, needs and expectations in the Autism and developmental disabilities communities" (Foster et al., 2019, p. 7).

² Nova Scotia Court of Appeal Releases Ground-breaking Decision regarding the Rights of Persons with Disabilities, Awards Largest Human Rights General Damages Award in Canadian History <https://pinklarkin.com/nscadecision/>

Inspired by a similar survey conducted in Massachusetts by Autism Housing Pathways³, the study is carefully framed to gather firsthand evidence of the needs and wants of individuals, as well as to help move the discussion around housing beyond just *needs*. All citizens have needs that shape where and how we live — and many of these needs are basic rights that Nova Scotia has a minimal obligation to meet. At the same time, citizens also have *wants and desires* that are often connected to the exercise of these basic rights and/or which impact our quality of life, which in turn make us healthier, happier, fuller participants in society. While we must address and meet the needs around housing for persons with disabilities, if we do not ask individuals what they *want*, then we are undermining their rights and humanity by assuming decisions about the nature of housing can be determined without their input and involvement.

There is no one-size-fits-all solution for housing. Instead, there are a plurality of situations, that demand a plurality of models and solutions that can adapt to the individual needs and wants of each citizen. This paper is therefore part of a larger effort to ensure that the complexity of lived experiences, backgrounds, preferences and desires of individuals is not being reduced to a set series of models for community living guided by a singular focus on *needs*, as determined by the needs of a housing system or process for “needs assessment.” A system-centred, needs-only focus risks decentering individuals from decisions about their lives, stigmatizing supported housing as a space where people are objectified as problems to be managed, removing the choice and desire that we all have the right to exercise.

Our survey illustrates the already well understood gaps between the services and supports autistic people say they need, and the ones they currently receive, as well as a strong desire for the basics that make independent and community-based living possible. It shows the interconnected problems of low income, un- and underemployment, and inadequate housing. Again, our approach, which sought to elicit not just needs but *desires*, helps to move the conversation beyond bricks and mortar, spaces and beds, toward the pursuit of full, rich, complex, self-determined lives where decisions about people are being made with those people. It also highlights the relative simplicity of many modifications to housing and fundamental supports autistic people say they need to live well, and with increased self-determination. The housing crisis for disabled people in Nova Scotia has clear, and in many cases well-known, solutions. While these challenges are often made out to seem daunting, this paper illustrates that the needs *and* wants of individuals with disabilities are expectations that we all have in life, reiterating that the decision to not act on such basic options is just that — a decision.

³ https://autismhousingpathways.net/wp-content/uploads/2014/05/AHP_Survey_results.pdf

AUTISTIC PEOPLE IN NOVA SCOTIA

OVER THE PAST TWENTY YEARS, there has been dramatic growth in the rate of Autism Spectrum Disorder diagnosis. In the year 2000, it was estimated at 1 in 150; the prevalence of diagnosis is currently estimated at 1 in 66 Canadians, meaning that a *conservative* estimate of prevalence in Nova Scotia would mean as many as 14,000-18,000 people *diagnosed* with Autism in this province (Autism Nova Scotia, 2017). This does not include the substantial number of people, particularly adults, who are struggling to access costly private diagnostics, but identify as autistic. There are many people living in institutional or congregate living arrangements, as well as a significant number of autistic young adults in Nova Scotia who would like to leave their family homes, but for the reasons outlined above have faced obstructions to their attempts or not tried at all because of the substantial wait times and restricted options. At the same time there is a growing number of children, who will become adults in the next 5-10 years, for whom the lack of options and pathways to community living will be no less a problem if it is not addressed now.

Autism can be defined in clinical terms, but autistic people have also worked to develop their own definitions that encompass autism as a disability a person can be diagnosed with, but also as an identity and a way of being in the world. As the Autism Self Advocacy Network explains:

Autism is a developmental disability that affects how we experience the world around us. [...] There is no one way to be autistic. Some autistic people can speak, and some autistic people need to communicate in other ways. Some autistic people also have intellectual disabilities, and some autistic people don't. Some autistic people need a lot of help in their day-to-day lives, and some autistic people only need a little help (Autistic Self Advocacy Network, 2021).

Autistic people might need help with instrumental activities of daily living, such as scheduling, budgeting, transportation, and food preparation, and/or activities of daily living such as personal care tasks i.e., relying on others for tasks requiring fine motor skills like shaving, and having prompts for showering. Autistic people might need accommodations in their physical environments, such as blackout blinds or soundproofing to reduce stimuli, interior doors that lock, or step-by-step instructions posted around the home for household tasks. The environments in which people live affect the person and their quality of life, autistic people included. Living independently (i.e., without any additional supports) or choosing a home from the mainstream housing market without modifications or supports is challenging for many. As a result, many autistic people go without needed supports, and many more end up over-supported, for example living in congregate settings with elderly residents, because adequate supports and modifications are not available in the less restrictive settings (Foster et. al, 2019; Hutchinson et. al, 2018; *Road to Inclusion by 2023*, 2021).

In addition to difficulties simply finding and accessing the supports and housing types they need, many autistic people lack the income to support their own households (Anderson et. al., 2018; Autism Nova Scotia, 2017, p. 11; Dudley et. al., 2015). There is a persistent correlation between disabilities of all kinds and unemployment, underemployment, and low income, and this is true of autistic people as well. Autistic people experience perhaps the most chronic unemployment and underemployment of any group of people who are marginalized in the labour

market.⁴ Disabled people generally “have lower median incomes, are less likely to be employed, and are less likely to hold a university degree than persons without a disability” (Wall, 2017). According to Statistics Canada, persons with disabilities make up over 40% of the low-income population; approximately 25% of persons reporting a disability in the low-income population earn “less than one-half of the median Canadian income” (Wall, 2017). People with mental-cognitive disabilities experience the lowest incomes and employment rates (ibid.). While Nova Scotia-specific data on labour force participation of autistic individuals is not available, we know that 30% of the population of the province reports having a disability, one of the highest rates in the country.⁵ Additionally, only 62% of people with a disability in Nova Scotia are in the labour force, and only 55% are employed (compared to 85% and 79% of Nova Scotians without a disability, respectively).⁶

Taking into account the large and growing number of autistic people in Nova Scotia, the slow progress on the development of community-based, person-centred, dispersed alternatives to congregate living arrangements, the diversity of support needs among autistic people, as well as the wider housing shortage in the province, it is clear that something must be done. A first priority is to understand the nuance of the need in terms of bricks and mortar *and* the services and supports people need to live the lives they *desire* in and around their homes. This is not a feelingless exercise of matching bodies to beds. It has to be a person-directed project of helping autistic people find or create homes that meet their physical, emotional, social, and mental needs (as we would expect for any person, regardless of ability). From this understanding, it is imperative to expand the stock of available, appropriate housing, but as important to ensure that wraparound supports are available, and to ensure that the people who need it can afford it.

⁴ Statistics Canada. Canadian Survey on Disability, 2012. <http://www5.statcan.gc.ca/olc-cel/olc.action?objid=89-654-X&objType=2&lang=en&limit=0..>

⁵ Accessibility Directorate. Prevalence of disabilities in Nova Scotia. <https://novascotia.ca/accessibility/prevalence/>

⁶ Ibid.

HOUSING OPTIONS AND SOLUTIONS ACROSS THE WORLD

FOR AUTISTIC PEOPLE, just what “appropriate housing” is depends on a variety of things. Occupancy type (shared with others vs. alone), building design, and the feasibility of adaptations all have an impact on sensory experiences and reactions to the environment (aka behaviour), contributing to the overall health and wellbeing of autistic people. Thus, using a holistic approach, building design and types of personal support must each be tailored and individualized to meet whatever needs are present (Brand, 2010).

While the abilities and sensitivities of autistic individuals vary greatly, and thus reactions to different environments can differ, an ideal home for anyone is generally a space that fosters a sense of security, safety, control, domestic comforts, and identity (Duignan & Connell, 2015). If housing is not suited to an individual’s sensitivities, it can trigger fear, disruption, uncertainty, and a sense of chaos which in turn leads to poor health and hospitalization (Duignan & Connell, 2015). Home adaptations can be necessary for creating a home environment individuals can trust will be predictable and supportive (Boyle, 2017).

A variety of basic residential options, with the potential to be further adapted, exist for autistic individuals. Broadly, these categories include: supported living, supervised living, group homes, and transitional living (Brand, 2010). All of these types are described in the next section, and there may be some overlap between them; all are in operation in Nova Scotia, but most are employed in a very limited way. Even small options group homes, which are probably the most numerous in the province, are still relatively rare compared to the demand that exists for them. It is also important to note that the types of supported housing arrangements outlined below may not align with the definitions developed in various housing programs or “streams” currently funded by the Nova Scotia Government. This means that there are differences between, for example, the Independent Living Program as a program stream with boundaries on funding and supports available through the Nova Scotia government, and the general definition of independent living as understood through the lens of best practices by an international movement. Readers interested in a more detailed examination of the specific programs and streams of housing available in the landscape in Nova Scotia can refer to Autism Nova Scotia’s 2018 Housing White Paper (Foster et al., 2019).

SUPPORTED LIVING

Supported living is when an individual lives in a place of their choosing, either alone or with a roommate, with some support from family and friends and/or from an off-site caregiver (Brand, 2010). Supported living aligns with a person-directed approach, and focuses on providing choices and building social connections. Although there are several types of supported living arrangements, the most common is for care providers to come into the individual’s home as needed (Cocks et al., 2016). The individual may live in a separate unit within the family home where a support staff comes in periodically to offer support. Other ways of providing support are through “smart home” assistive technology (e.g., Alexa, thermostats and other appliances that respond to the user’s habits, two-way communication tools) and support from a family member and/or a service provider

(Boyle, 2017). This type of supported living can extend beyond the family home. An individual may choose to move out of the family home and rent their own apartment, purchase a home, or even live with a different family. In any supported living model, housing *can* be separated both financially and organizationally from support staffing (Cocks et al., 2016). For independent supported living to work well, individuals need access to skilled support staff, control over the recruitment and scheduling of support staff, and support to build friendships and meaningful community roles, as well as support to manage difficult relationships (Bigby et al., 2017). Extensive research and evaluation demonstrate that supported living is effective for most individuals, regardless of ability, and is a less costly model than group homes (Bigby et al., 2017; Cocks et al. 2016; Cocks et al. 2017).

COMMUNITY-BASED SMALL OPTION HOMES

Community-based small options living is an accommodation where numerous (usually 3 or 4) people with support needs intentionally live in the same building, and the majority of support is coordinated and comes from a source other than immediate family. This supported housing type is often determined by the service type, rather than neurotype. Sometimes the home is leased or self-owned, and the leaser or owner of the home may be the individuals living in the home, a larger residential service provider with multiple homes, or a small, incorporated entity that only manages the operations of a single home. Depending on the tenure type, the support may be live-in, if the option to offer a separate living space for the caregiver is viable. Intergenerational housing, in which seniors are co-located with younger autistic adults, is another emerging practice in community-based small options—although this model is only available in some areas (Boyle et al., 2016).

An example of an innovative model of community-based intergenerational housing comes from Phoenix Arizona's 29 Palms.⁷ Included at 29 Palms are 15 units for seniors and six units for autistic adults. Utilizing a mix from private and public funds, 29 Palms was created to fill an affordable housing gap for seniors. Before moving in, each senior undergoes training so that they can understand the needs of their autistic neighbours. For some autistic adults, this model can also serve as transitional living (see below), as life skill training and independent living are goals of the project (Steele & Ahrentzen, 2016).

⁷ Other examples can be found at <https://www.autismhousingnetwork.org/resources/>

TRANSITIONAL LIVING

Transitional living is a model whereby housing is part of intensive life skills training. Transitional living is meant as a stepping stone for residents, who use the living arrangement to learn the skills that they need to live independently (Boyle, 2017), rather than a permanent place to live. In some cases, transitional living can include vocational courses, college support programs, financial literacy, basic housekeeping, or the skills needed to move on to further education. In most transitional living setups, the housing creates intentional communities. Transitional living, in some cases, includes residents with and without disabilities, each with their own living space within the community.

Rural housing facilities have been built that facilitates active involvement with the land and animals, all while maintaining a strong sense of community involvement and cohesion (Boyle, 2017).

CO-HOUSING: MULTI-UNIT, INCLUSIVE UNIVERSAL DESIGN COMMUNITIES

Another approach is the development large, inclusive, multi-unit housing that includes autism-friendly universally designed features incorporated into the building's construction (Boyle, 2017). The apartments, condos or homes that comprise such complexes can be occupied by residents of any neurotype, and people with or without disabilities. A facilitator, a neighbour, or both, are paid to facilitate connections between residents and provide support to those who need it (Boyle, 2017). In the future, zoning that includes a requirement that a percentage of units have autism-friendly and accessible design features already incorporated could pave the way for more inclusive housing and communities like these.

An innovative example of co-housing is “Sweetwater Spectrum”, a non-profit organization in Sonoma, California dedicated to exploring, building, and evaluating a community conscious housing model for autistic adults. It is a supported living community with a central common house that integrates a community space, kitchen, exercise studio, media room, and a library. This model includes an organic farm that serves local businesses and an enrichment program intended to foster living a “life with purpose” through both individual choice and community engagement (Sweetwater Spectrum, n.d.).

PERSON-DIRECTED PLANNING AS A FOUNDATION FOR HOUSING AND SUPPORT

There are autistic people for whom conventional housing cannot work, because of behaviours that challenge the infrastructure or support providers and the housing stock available to them. Still, those who design housing for autistic people insist that proper “modifications to the home can often reduce the cost of supports” (Boyle, 2017, p. 26). There is increasing recognition that autistic individuals should have the opportunity to collaborate in the identification and design of necessary and helpful modifications. Gaudion et al. (2015) have developed a resource to support designers and service providers to work with non-verbal and unreliably speaking autistic people, and people with learning disabilities, to include them in the design process. In their approach,

“particular attention is paid towards the careful selection, adaptation and development of collaborative design methods for adults with ASD, their family members, or support staff to be involved. By working beyond the boundaries of a neurotypical culture, the project aims to support the greater goal of improving the everyday experiences of people living with Autism by breaking down the barriers to participation” (Gaudion et al., 2015, p. 49).

Similarly, Braddock and Rowell (2011) recommend a five step Environmental Assessment and Action Plan which includes:

- 1 Involving the individual to identify their challenges.**
- 2 Including support providers to identify their challenges.**
- 3 Assessing the home to identify what isn’t working.**
- 4 Learning about and designing common home modifications and strategies for specific challenges.**
- 5 Making an Action Plan that is appropriate to the unique situation and circumstances.**

Consultation with individuals and their families is thus imperative in selecting, adapting, and developing housing for autistic people (Hole, Robinson, Stainton, Lige, & Crawford, 2015). With this person-centred approach in mind, more specifically, cultivating spaces that are accessible and inclusive requires considerations for the safety, privacy, choice, and independence of autistic people, as well as being familiar, clear, durable, and affordable (Steele & Ahrentzen, 2015). Minimizing sensory, privacy, choice and independence, durability and affordability are all common themes that can contribute to an autism-friendly design (Steele & Ahrentzen, 2015). The appropriate design with clear, simple, and predictable layouts with clearly defined uses and functions can support people in their daily lives and enhance their quality of life (Nagib & Williams, 2017). In certain cases, if the proper environmental accommodations are in place, then living independently may become a possibility where it did not seem possible before (Steele & Ahrentzen, 2016).

THE HOUSING NEEDS AND DESIRES SURVEY

The data below are from a multi-modal survey conducted in 2020-21 with people who identify as autistic or as being a person with autism. All are aged 16 and older and live in Nova Scotia. The research team aimed to recruit 500 participants but fell short of this goal, with a total of 104 at the end of recruitment. We attribute this shortfall partly to the COVID-19 pandemic, which caused “survey fatigue” across the world (Field, 2020) and prohibited the in-person events at which we planned to promote the survey. A further reason is that there is no central, reliable database of autistic people in Nova Scotia, and recruitment had to take place through open calls made by Autism service providers.

The survey was designed collaboratively, with Dr. Karen Foster leading the first draft after consulting Autism Nova Scotia staff about the organization’s objectives and after a research assistant conducted preliminary interviews with five autistic individuals who are connected to Autism Nova Scotia, for example as service users or volunteers. These interviews sought to get a sense of the major issues and challenges around housing, as well as the diverse needs, wants and abilities that the survey’s design would need to consider. Major recommendations out of this process included pilot testing the survey carefully with autistic people, to ensure there was no ambiguous language; offering the survey in multiple formats (phone, online and paper); and enabling respondents to use the assistance of their own helper or someone from Autism Nova Scotia or the research team. We also adopted a recommendation to include visual aids (such as images of different housing types and communities to help respondents identify the kind they live in) on several questions, and to include many open-ended questions and opportunities to explain or qualify answers to multiple-choice questions. The survey appears to have been well-received, with no noted problems answering questions, and rich qualitative data in the open-ended questions.⁸

Recruitment took place through a number of channels, including social media (Twitter and Facebook posts from Autism Nova Scotia), Autism Nova Scotia newsletters, and direct promotion to Autism Nova Scotia’s chapters across the province and to group homes. The age cutoff of 16 was chosen in order to target people who might reasonably be thinking about where they will live as adults, and could conceivably move out, get a job etc. There was no upper limit on age as many autistic people do not live how they want to well into adulthood and even old age, but they still might have aspirations to do so. Respondents to the survey

⁸ There was a formatting error on a portion of the paper-based surveys, where more than one response option was displayed on the same line for several questions. In most cases, it was possible to discern the ‘correct’ answer based on how subsequent questions were answered. In cases where it was not possible to discern, the data for these improperly formatted questions is omitted.

include participants with range of abilities and needs; we did not *screen* for levels of affectedness, or any other traits/characteristics related to autism nor to those of ASD diagnostic measures. The final sample is not, and was not intended to be, a statistically representative sample; it is a convenience sample.

As mentioned, participants were able to complete the survey online, on paper, or over the telephone. In the end, the majority opted to complete it online (92), followed by paper/mail (8), with 4 completing the survey by phone. All participants had the opportunity to enter their email addresses into a draw for one of five \$100 Sobeys Gift Cards.

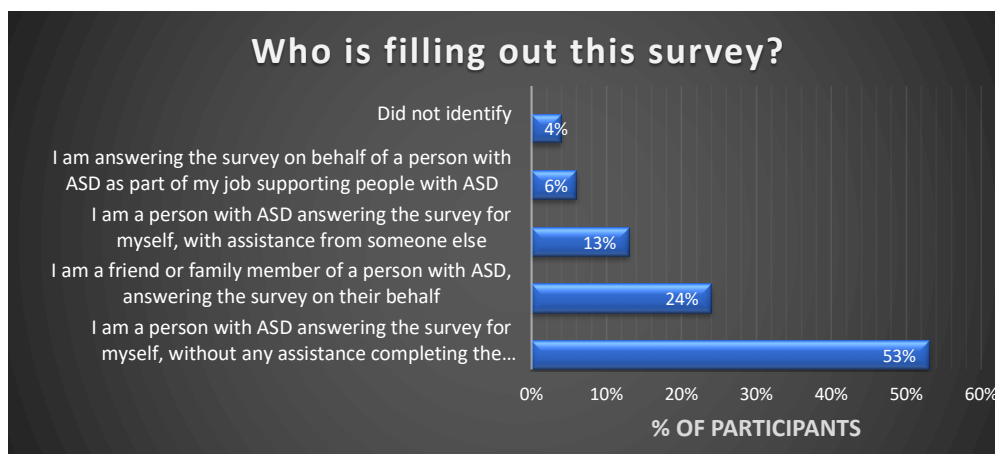
LIMITATIONS

The small size of our sample does not allow for much detail in terms of other identities that intersect with autism, particularly through the quantitative data. However, qualitative responses offer some additional insights into the “intersectionality” of age, geography, class, gender, and disability. In other words, the demographic variables give us a sense of who completed the survey and how skewed its results might be compared to a perfectly representative sample, but they also allow us to consider how housing needs and desires are shaped by intersecting oppressions, such as racial inequity, cisheteronormativity, and income inequality (see Crenshaw, 1989). The small sample size and non-representative character of the data do not enable a full intersectional exploration of housing needs and desires. This is fertile ground for future research, as the experience of autistic people in Nova Scotia and elsewhere is most certainly shaped by the identities that intersect with autism (Kim, 2021). We also have no way of knowing how well the responses from helpers represent the needs, but especially the desires, of the people on whose behalf they were responding.

SAMPLE CHARACTERISTICS

After four months in the field, the survey had 159 responses. Of those, 104 were complete. Because participants could withdraw their participation by closing their browser window and leaving the survey, incomplete surveys were considered withdrawn surveys, and are not used in this analysis. Here, we report the demographics of survey respondents, and further below we are able to highlight some of the ways in which demographics might intersect to shape experiences. As shown in Figure 1, just over half of the respondents said they completed the survey independently (53%). The next most common approach was for a friend or family member to complete the survey on behalf of an autistic person (24%). Thirteen percent of respondents were autistic and completed the survey with assistance from someone else. Six percent of surveys were completed by someone as part of their job (e.g., a support worker in a group home).

FIGURE 1 | N=104



Three-quarters of respondents (75%) were aged 16-34; the largest single group of respondents was between the ages of 25 and 34 (45%), and a further 30% were 16-24. The rest were over 35. The median age was 25.5.

FIGURE 2 | N=104

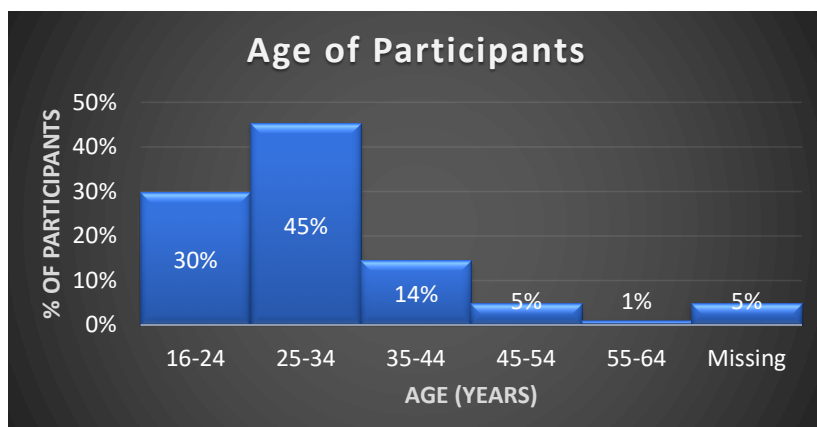
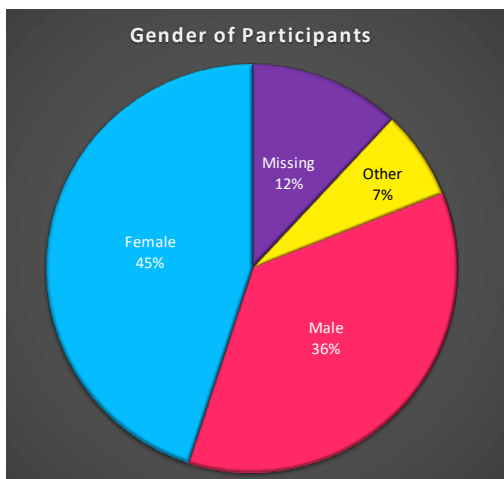


FIGURE 3 | N=104



Respondents were asked, in an open-ended question, to self-identify their gender (Figure 3). There were slightly more people who answered “female,” “girl,” or “woman” (45%) compared to those who answered “male” or “man” (36%). Twelve percent of respondents opted not to answer the question, and 7% responded with something other than the binary, such as “non-binary” or “variant”. This is an interesting gender breakdown, as it is widely known that men are at least three

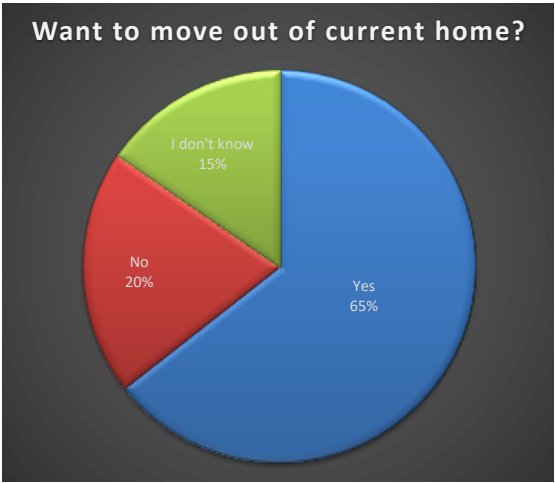
times more likely than women to have an autism diagnosis (Loomes et al., 2017). The overrepresentation of women in this sample may be due to the fact that women are more likely to participate in surveys than men (Curtin et al., 2000).

HOPES, DESIRES AND EXPECTATIONS

This study was conceived in opposition to the detached, technical approach often taken toward evaluating the gap between housing need and availability for people with disabilities. As noted earlier, this discussion often revolves around “individuals”, “waitlists”, “spots” and even “beds”, which reduces the problem of supportive, community living for people with disabilities to a simplistic equation where success depends on a number of generic places — the Disability Support Program calls them ‘beds’ — matching up with a number of generic people. In contrast, we want to see autistic people as unique members of unique communities, with hopes and desires that shape where and how they want to live just as much as their needs for particular kinds of support — just like anyone else.

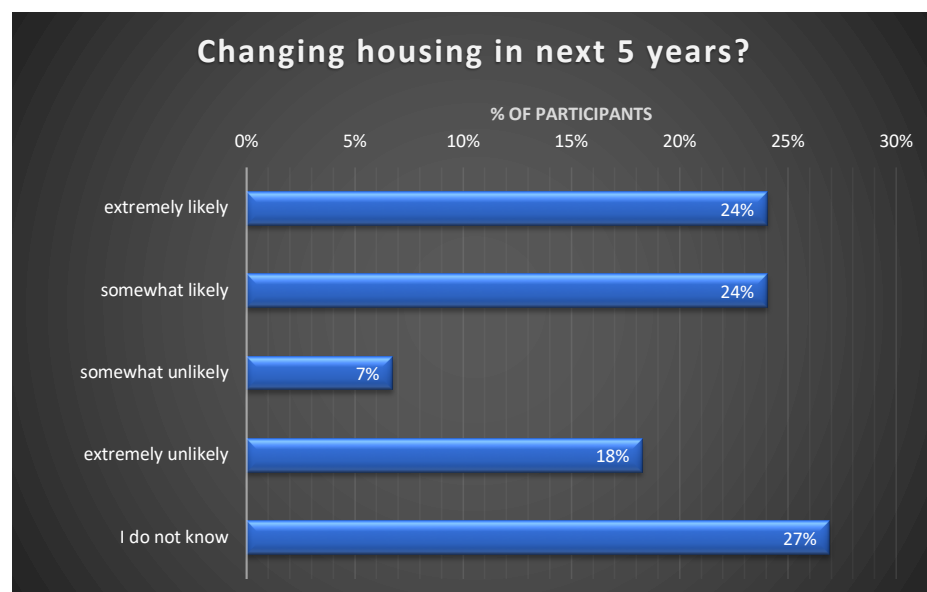
For people without disabilities, the choice of a home (where the privilege to consider it a choice exists) is well understood to depend on social relationships, lifestyles, tastes, and mobilities; we do not simply accept the first available “space” in reach. While a tight housing market in Nova Scotia means that more people have limited choices, and increasing numbers have no house at all, the fact remains that ideally, home is something far more complex and personal than a physical place. Given the study’s commitment to foregrounding hopes and desires, this report leads with findings on those themes and looks at respondents’ current living arrangements and resources later.

FIGURE 4 | N=104



Two-thirds (65%) of all respondents would like to move out of their current household (Figure 4). A further 15% said they don’t know whether or not they would like to move out. But just under half think it is likely to happen in the next five years. As shown in Figure 5, 48% of respondents said it was extremely or somewhat likely they would leave their current household in the next five years. They were more likely to say they didn’t know (27%) than to give a definitive answer. The rest said it was extremely unlikely (18%) or somewhat unlikely (7%).

FIGURE 5 | N=104



Several open-ended questions, in which survey respondents were asked for more details, in their own words, about what they liked and did not like about their current home, as well as why they thought they would or would not move in the next five years, provide some more information to assist with interpreting these results. Asked what they like about their current home, the top explanations were:

- **Liking the people they live with and around (including neighbours),** mentioned by 20 respondents.
- **Having their own space, usually a bedroom, where they can retreat when they want to be alone and over which they have control,** mentioned by 16 people.
- **Having a quiet home and neighbourhood,** mentioned by 15 people.
- **Enjoying their independence and freedom to do what they want, when they want (including going to bed and waking up, making their own schedule, deciding what they eat and what they do for fun),** mentioned by 14 people.
- **Their home's location, close to other places they like to go, including natural spaces, retail, bus routes,** mentioned by 13 people.
- **The size of their home, usually that it is large with lots of space to move around and spread out from others,** mentioned by 12 people.
- **Valuing their privacy — inside their home, from others who live with them, and outside their home, from neighbours and passersby,** mentioned by 11 people.

Other qualities, mentioned by fewer than 10 respondents each, included aesthetic qualities (e.g., colours, coziness), supports in the home (e.g., measures to reduce stimuli, paid assistance, unpaid assistance), cost or affordability, safety (e.g., secure buildings, low-crime areas), the home's layout (few stairs, where bedroom is), ability to have pets, amenities or possessions, such as mail in the building or having their own gaming console, yards, comfort, and stability (i.e., living in the same place for a long time).

Taken together, and analysed thematically, **the responses to this question point to the importance of both support and independence — respondents care a lot about who they live with (as we all do), and like having supportive, unintrusive people around. But they also say they need to be able to make choices for themselves, and they need to be able to retreat to privacy and quiet when they want to.**

This emerges as a tension that is important to negotiate and mitigate: the tension between needing support as much as one needs to be left alone sometimes.

For example, one respondent who lives with their parents said, “I like being able to do what I want when I want, and having support to learn new things.” Another, prioritizing the independence and privacy aspect, said “I have my own space and am able to do what I want (to some extent) within it, without my privacy being invaded, most of the time.” Another, focusing on the people and support, said “I have the comfort of having my parents around, and I do have people to talk to. I don’t need to pay for everything in the house.”

Answers ranged from very brief to quite expressive and detailed. In either case, most answers mentioned multiple themes. For example, mentioning the themes of stability, people, privacy, freedom, support, and pets, one person said: “I have lived here since I was five. There are tons of memories here and I have my family close to me for support and I feel comfortable with them. There is privacy in the rural aspect. I have my own room, am able to have my 3 cats and have all my needs met.”

Asked what they *dislike* about their current home, respondents gave answers that further reinforce the importance of people, control over space, quiet, and independence/freedom. The most commonly *disliked* qualities were:

- **They cannot get away from the people they live with, and/or that they lack the independence to do what they want, when they want, mentioned by 17 people.**
- **Their home is loud, with noise from other people (e.g., roommates or family in the same space, or people in neighbouring apartments), or noise from traffic, appliances or construction, mentioned by 16 people.**
- **They live with other people they find difficult to be around or interact with— from family that are too intrusive or controlling, to scary superintendents, to roommates with more serious behaviours, mentioned by 13 people.**

Other answers, mentioned by fewer than ten people, included the high cost or unaffordability of the home; physical aspects of the home, such as having too many stairs or having old furnishings; the home being in need of repair; needing to share space or amenities with others; and the home’s location — usually that it is too far from things they would like to do. Several people mentioned simply feeling “too old” to live with their parents, and tied this feeling into the more general issue of needing more independence but being hemmed in by support needs.

As one respondent explained, highlighting this tension between support and independence, “I think I am too old to be living at home and sometimes my parents and I want to do different things or need some space and I cannot get that right now because I live with my parents and need them to drive me and help me get groceries and help me plan.” Another, in a similar situation, confided: “I dislike that I have to live with my family. I dislike that my mom has to work to help support me even though she has very bad health problems and is sixty-five. She should be

retired but she can't because she helps me to survive." A third respondent offered some concrete examples of how the tensions can rise when living with family as an adult (with some details removed to protect anonymity):

"I love my family, but as an individual, I often feel that I am a guest in my own home. I often leave possessions out in the living room [...] many times it will either disappear (carried off to my room and placed somewhere I am not able to easily find) or I am otherwise encouraged to put everything away. [...] Although my parents are usually very patient with my possessions being in common space, they do bring it up from time to time—I usually try to contain my mess to a space around the chair I usually occupy, which I lovingly refer to as my 'nest.'

Privacy is another issue. I share a bathroom—the main one on the floor. My parents will also occasionally forget to knock before entering my room, or knock and enter without waiting for a response. This has resulted in some stress on my part. The house is also quite a distance (about 15 mins to town by car) from ANYTHING that could be considered a suitable place to find food, public transport or entertainment (which is lacking in my community anyway). It works for me though, because I prefer privacy."

In later questions, the same tension comes up repeatedly: people who live with and enjoy their parents' support also find it difficult to have a social life with their parents around. Those whose parents do not want pets are disappointed that they can't have a dog or cat.

The 65% of respondents who said they want to move out of their current home (Figure 4) cited many of the likes and dislikes above as motivations to move out, but many, particularly those who lived with their parents, simply felt it was time—they were adults, some were going to post-secondary school or getting jobs, and it felt appropriate to live elsewhere. Those who said it was *likely* they would move out (Figure 5) commonly pointed to their own growing ability to support themselves, and their parents' support for them moving out; many of these respondents pointed specifically to the structured steps they had taken with their parents to prepare for an independent household—such as getting Independent Living Support funding, or taking a course to help build independent living skills. Others believed the unaffordability of their current home would eventually push them out, as rents increased especially in Halifax Regional Municipality.

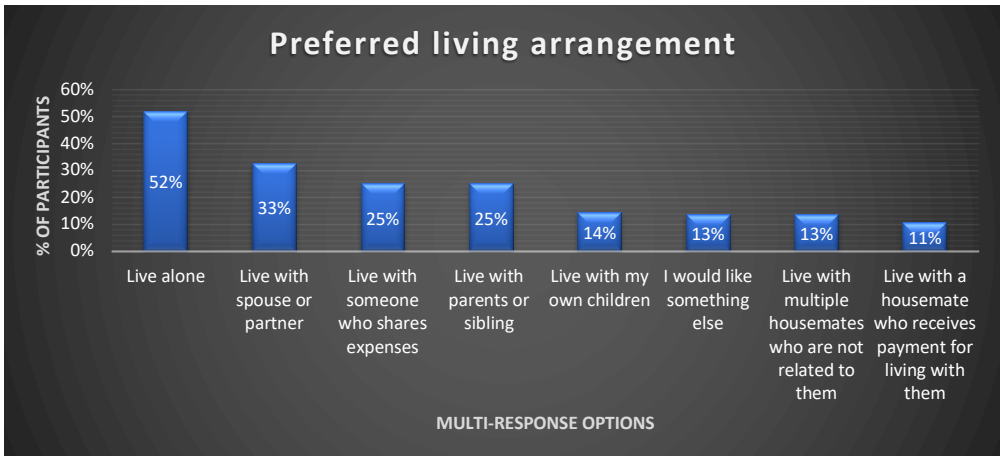
Relatedly, those who said it was **unlikely** they would move tended to point to financial barriers as the reason why.

As one respondent explained, "If I move, [it will be because I am] evicted for not paying the rent. I do not expect to be able to do better. I can barely do this. If evicted, I have no idea where I will go. This place has been carefully chosen and changed to match my needs, and I have established a routine here. I don't want a supposedly nicer place without any of the things that I actually care about, ground floor, good neighbours, a garden to make, furnishing and storage areas that I need, and so on." Another described the long process of trying to change homes on a lower income: "Financial barriers. We have been looking for a long time but there a lot of barriers. I'd like to get a job to help but I don't know how yet, and my mother is trying to find another job as well amidst the bills she has to pay, which are the barriers, but I know she wants to move as well, although likely won't happen for a while unfortunately."

All respondents, regardless of whether or not they wanted to leave their current home, were asked about their preferred living arrangements. They were reminded it might be the way they live now, or it could be something different they want in the future. In the first question in this series, they were asked about who they would like to live with, and they were allowed to select multiple options.

About half—the largest proportion—said they would prefer to live alone (Figure 6). Thirty-three percent said they would prefer to live with a spouse or romantic partner, and one-quarter each (25%) said they want to live with someone who shares expenses or to live with their parent(s) or sibling(s). Fourteen percent said they would prefer to live with their own children. Just thirteen percent wanted to live with non-relative housemates, and 11% wanted to live with a housemate who receives compensation for living with them. Thirteen percent said they wanted something other than these options.

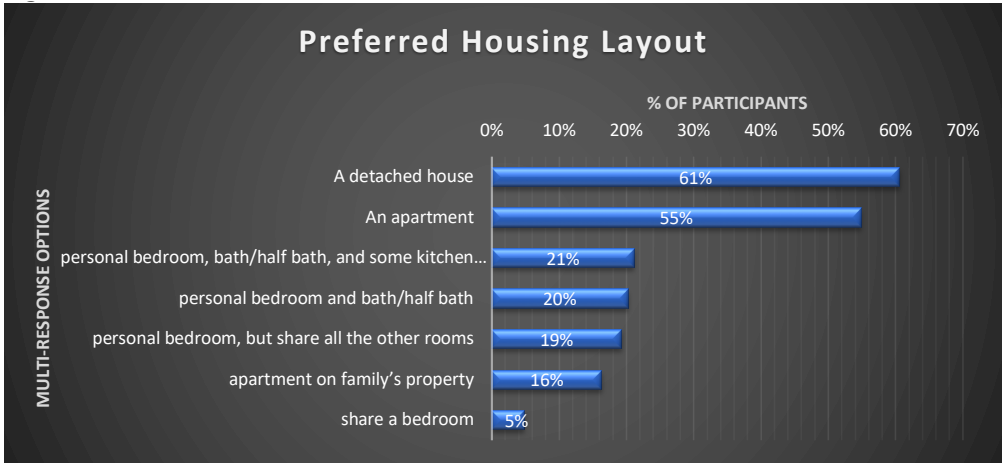
FIGURE 6 | N=104



Of those who said they wanted to live with housemates, most said they had no preference regarding whether or not the housemate was autistic or had a disability. The rest were split evenly between preferring an autistic housemate or someone with another disability and preferring someone who does not.

Respondents were asked to think about what kind of a house they would like to live in, and how they would like to live in it—e.g., “I would like to live in a house” or “I would like to have my own bedroom, but share all the other rooms”. They could select more than one response as most were not mutually exclusive. As shown in Figure 7, most said they would prefer to live in a detached house (61%) or an apartment (55%).

FIGURE 7 | N=104

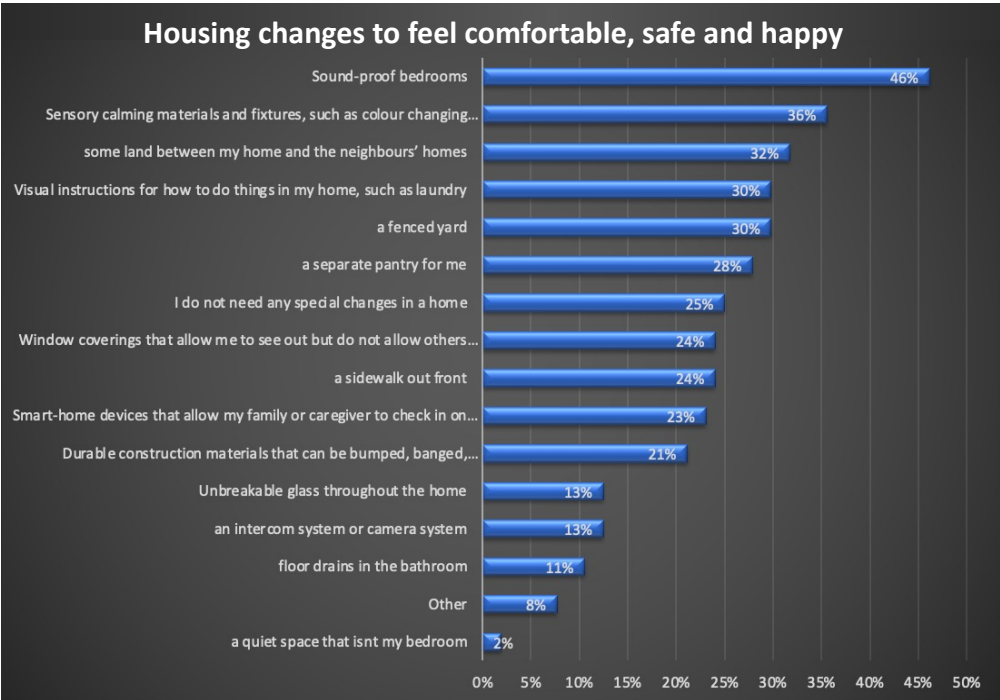


About one in five respondents said they would like to have their own personal bedroom, and roughly the same proportion wanted to share all the other rooms, or have their own bathroom, or have their own bathroom and kitchen space (19-21% each). Sixteen percent said they would like to live in an apartment on their family’s property (a selection that likely depends to some extent on having a family with property where this is possible), and just 5% said they would like to share a bedroom.

Asked what kind of ownership arrangements they would prefer, 40% said they wanted to live in a home that they or their family owns, 24% said they would like to live in a home owned by someone else (or an organization), and 34% were not sure.

Respondents were also asked about the kinds of changes or special features their ideal home would require in order for them to “feel safe, comfortable and happy in it.” As shown in Figure 8, echoing the qualitative responses about likes and dislikes, *quiet* is very important, with sound-proof bedrooms and other quiet spaces being the most commonly selected option (48%). (The option listed was “Sound Proof Bedrooms”, but two respondents wrote in “a quiet space that isn’t my bedroom” so we added these to the first option in the table below.)

FIGURE 8 | N=104⁹



Relatedly, over one-third said they needed sensory calming materials and fixtures (36%) and slightly fewer said they wanted some land between their home and their neighbours' (32%). Each of these top three changes relates to the themes of privacy and quiet that were so commonly mentioned in the free-text questions discussed earlier.

Moving away from the physical space to focus on necessary supports, the survey asked respondents to select a statement that best reflected their support needs. The results are summarized in Table 1.

TABLE 1 | N=104

HOW MUCH SUPPORT DO YOU NEED TO BE HAPPY, COMFORTABLE AND SAFE?

I am able to live independently, but I need or would benefit from someone checking on me and helping me with specific tasks.	50%
I am able to live independently. My autism does not mean I need support in order to live on my own.	22%
I cannot live independently, but I can be alone in my home for up to 3 hours at a time.	13%
I need someone present at all times, but I could share one support person with other people.	8%
I need one-on-one (or more) support at all times, but the support person could sleep during the night.	4%
I need one-on-one (or more) support at all times, including someone to stay awake overnight to support me.	3%

⁹ In this and any other chart labeled with "multi-response options", percentages will not sum to 100% because respondents could choose multiple answers. The % in the chart refers to the % of all respondents who selected the response.

As shown above, about half of respondents said they can live independently with minimal support (50%) or no support (22%). Thirteen percent said they could be alone for up to 3 hours at a time, and smaller proportions would need 24/7 support (8%) or one-on-one support most or all of the time (3-4%).

Looking more specifically at the kinds of support needed, two questions asked what supports respondents currently *need*, and all the supports they currently *receive*. The responses to both questions are shown in Table 2 to highlight the gap between needed and received supports. We have also included this table as a bar chart in appendix I in case that is more intuitive for some readers.

TABLE 2 | N=104

Support Type	Needed	Received	Needed-Received Support Gap
Money management	64%	40%	24%
Financial support for food	63%	46%	17%
Help with big life decisions	57%	44%	13%
Support through transitions	52%	32%	20%
Finding a job	51%	31%	20%
Finding suitable housing	50%	15%	35%
Scheduling	50%	36%	14%
Transportation and bus schedule	50%	38%	12%
Help cooking	47%	38%	10%
Support with cleaning	45%	36%	10%
Support for relationships and sexuality	44%	15%	29%
Sticking to a healthy lifestyle	43%	28%	15%
Help keeping a job	40%	18%	22%
Socializing and meeting people	39%	27%	13%
Help making daily decisions	37%	37%	0%
Support at school	22%	14%	8%
Help with academic studies	21%	17%	4%
Special diet	15%	12%	4%

As can be seen above, **the area of greatest reported need is in money management and financial support for food.** To some extent these two are related and likely suggest that many respondents are contending with limited income (and, given the low employment rates in the sample—44% were unemployed—this is a safe assumption) and have internalized the misleading notion that in order to live on a low income people simply need to be smarter about money. In other words, ***needing support with money management may well be about recognizing a deficit in understanding finances, but it may also be about trying to live below the poverty line, which is rarely a matter of being savvy and usually a function of social inequalities beyond the control of any person.***

Over half of respondents said they need help with big life decisions (57%), support through transitions (52%), and finding a job (51%). About half said they needed support finding housing, making and sticking to a schedule, and using public transportation. Just under half need help cooking (47%) and cleaning (45%). Slightly less need support with their relationships and sexuality (44%) and sticking to a healthy lifestyle (43%). Forty percent said they need support *keeping* a job, and 39% said they need support to socialize and meet people. Thirty-seven percent need help making daily decisions. About one in five said they need support at school or support with their studies in general (21-22%). Fifteen percent need help with a special diet.

Looking at the third column in Table 2, we can see where the greatest gaps exist between needed and received supports. The largest discrepancy between the supports needed and support received is around housing (35% unmet need). The second largest gap is around healthy relationships and sexuality (29% unmet need), and the third is in support for money management (24%). Other gaps can be read from the table, but one outlier is worth further discussion: 37% said they need help with daily decisions, and the same proportion said they receive this help. Like in all the other gaps, this does not mean there is no need. It may be an indication that some people are receiving supports they do not really need, and others are not receiving supports they do need. *The case of help with daily decisions is perhaps easiest to comprehend by way of an example: take the common situation of adults living with their parents longer than they would like to. They might be getting lots of “help” with daily decisions that they could actually do without, and which strikes them as interference rather than assistance.*

In any event, Table 2 shows that support gaps do exist, and taken into consideration alongside the other data from this survey, it paints a picture of an overall deficit in the support landscape, which is all the more disappointing given the simplicity of so many of the supports, and the conviction of so many of the survey respondents that they can live independently with minimal supports and physical changes to a home.

Getting housing right in Nova Scotia is critical to allowing autistic people, like all people, to flourish. Near the end of the survey, respondents were asked if they had any major goals or plans for themselves in the future, as “housing is just one part of life.” The responses, as expected, have a lot to do with home and housing, as the foundation for everything else. Many of the answers are optimistic and simple: people who took the survey want to be independent but supported, to learn to drive a car, to go to school and/or start a career, to develop a healthy, reliable social network and deepen relationships with significant others. Many mentioned goals neurotypical people might take for granted — trying out dating for the first time, wearing jewelry, or getting a pet. Here are some examples that illustrate the importance of goals that might be taken for granted:

"I want to be independent. I want to have a stable job in my field of study and live somewhere in Nova Scotia or Atlantic Canada. I would like to see what dating is like, and perhaps someday even have a romantic partner. I would like to have more pets (like a dog). I want to feel more like myself and better about myself. Change my wardrobe over time, eat healthier, maybe even wear jewelry sometimes! But most of all, I just want to be happy and stable, both in where I live and in my mental health".

"I do not believe that there will ever be support for me enough to have a meaningful life. I used to want to raise children and work in [my] sector. I used to want to have many close friends. Cook great food and share it. Dance and swim. Make an impact on other people's lives. I had plans to make these 'Specific, Measurable, Achievable, Realistic, and Timely' (or whatever). Since the fall there has been a decline. I just don't want to die too early and to get some rest here and there, maybe some pain relief. Absolutely nothing else feels realistic anymore."

"I want more friends, a group of people who regularly call me and check in on me but in a way that is as a friend, not as a support worker or something like that. I want a pet cat too."

"I'm autistic enough to struggle with burnout and being unable to drive, but not autistic enough to receive any financial aid. It's very difficult to earn enough money for my share of the bills. If an autism diagnosis was enough to make people automatically qualify for financial aid, housing would be MUCH more accessible."

"More hours of work, live with my boyfriend, be more independent but have help when I need it, travel."

"I want a job making videos, I would like to go to film school. I would like to live away from my mother but need help to care for myself."

The last two answers, like others to this question, recall the aforementioned tension between independence and support—needing the freedom to make choices and have control but also needing support with certain tasks and decisions. This tension is, evidently, central to not just housing and home, but to life in general for autistic adults.

Respondents were given, finally, a chance to add anything else they wanted about how their goals and plans are affected by where they live. Their answers return to the same themes already noted: for some, the home's location makes it difficult to access friends, school, work, and activities without relying on someone

to drive them; for others, sensory sensitivities — to the noise of neighbours and housemates — take up a lot of their time and compromise their ability to get everyday things done. For several, in contrast, the support they receive from parents affects their goals in a positive way — they have parents who are working with them to help them reach their goals. And for others, the location of their home is a positive too; they are close to work, school, friends and/or activities, and can get around independently on foot or by public transit. Thus, what counts as a good house and location might be subjective and individualized, but it is clear that in order to facilitate a person’s goals, it should be close to the things they have to do and like to do, it should be affordable, it should be adapted to any support or sensory needs, and it should have the right mix of support and independence.

THE WHO, WHAT AND WHERE OF HOUSING

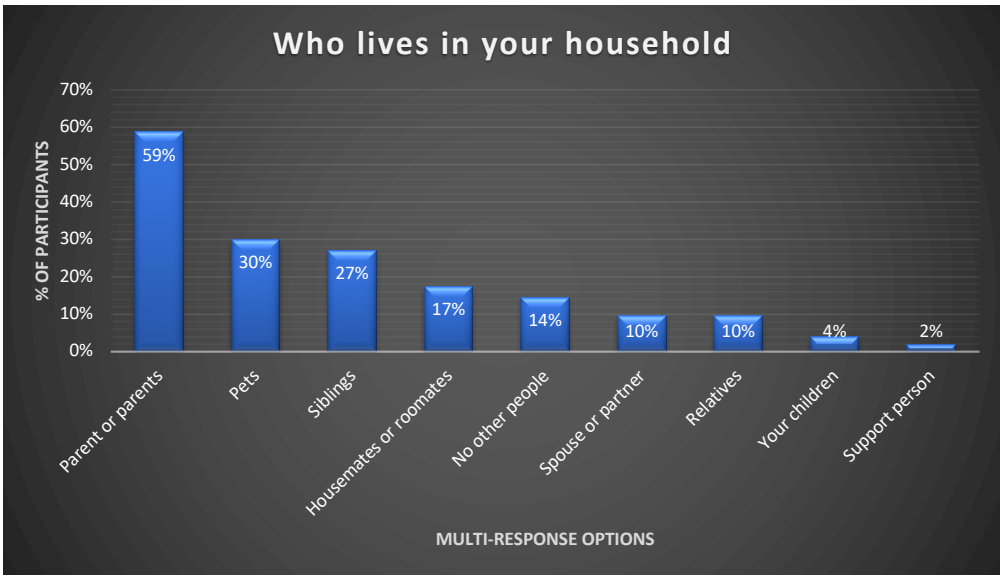
There was great variation in the sample in terms of what kinds of homes respondents currently lived in, where, and with whom. As shown in Table 3, the largest proportion of respondents (41%) described their current home as a single, detached home. The next two most common responses were apartments — 12% lived in a large apartment complex, and 10% lived in smaller apartment complexes (of five floors or fewer). Five percent each lived in row/town houses or duplexes, or offered a description that did not fit any of the survey options. Four % lived in apartments or flats in houses, and 2% lived in mobile homes. Very small proportions lived in congregate facilities or condos.

TABLE 3

Type of home (current)	
A single, detached home (not a duplex or an apartment, etc.)	41%
An apartment in a large building (a building with more than 5 floors)	12%
An apartment in a smaller building (a building with 5 floors or fewer)	10%
A row house or town house	5%
A duplex	5%
Other	5%
An apartment or flat in a house	4%
A mini-home or moveable dwelling (for example, a trailer)	2%
A large facility that is reserved for people who need supports with daily living	1%
A condominium (condo)	1%

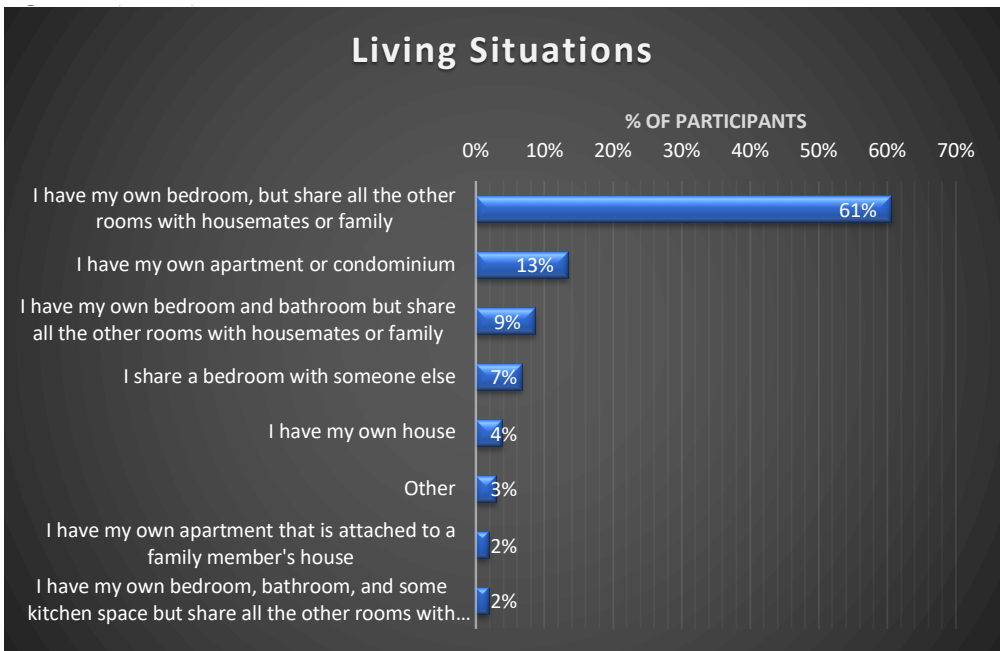
Most people who answered the survey lived with others. Household sizes ranged from 1 person to 50 (a congregate setting), but the median household size was 2 people. Fourteen percent of respondents lived alone (Figure 9). Over half lived with at least one parent (59%), over one-quarter (27%) lived with siblings, and 17% lived with roommates or housemates other than relatives. One in ten lived with a spouse or romantic partner, and another 10% lived with relatives other than parents or siblings. Four percent lived with their own children, and just two percent lived with a support person. This does not mean that only two percent had support person working at their home, but that only 2% said this person lived there full-time.

FIGURE 9 (N=104)



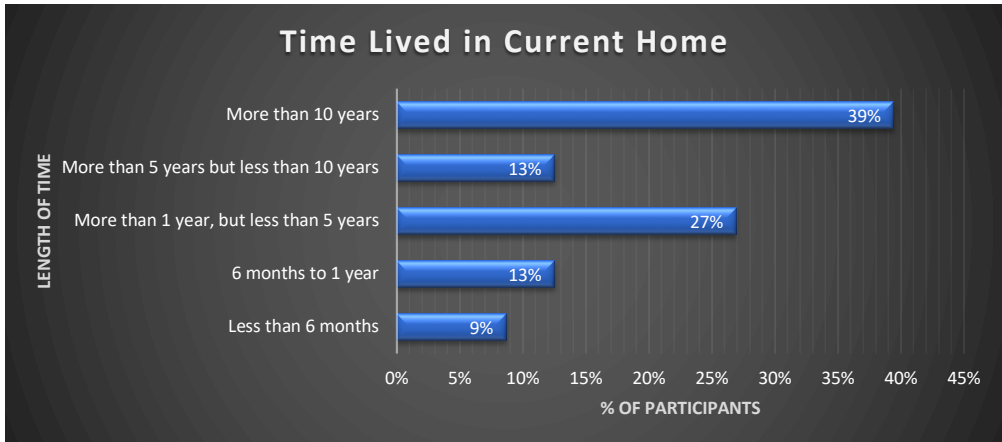
Looking at the arrangement people had with the others in their homes (Figure 10), most respondents (61%) had only a bedroom to themselves, and shared all the other rooms with their housemates or family. The next most common arrangement was having their own apartment or condo. A further 9% had a bedroom *and* bathroom to themselves, and shared all other rooms. Seven percent shared a bedroom with someone else (notably, in most cases this was likely a spouse). Just four percent had their own home. Other arrangements, such as living in an apartment attached to a family member's house, or having some kitchen space in addition to bedroom and bathroom in a shared home, were less common (2% each).

FIGURE 10 (N=104)



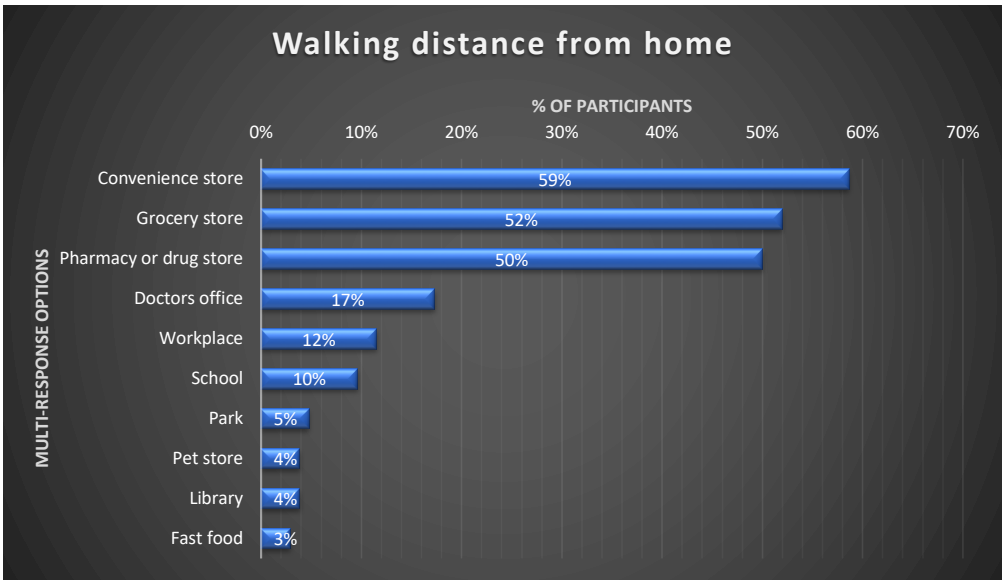
As Figure 11 shows, most respondents had been living in their homes for a long time, with over half (52%) saying they had been there more than five years (and of those, most had lived in their homes over ten years). A further 27% lived in their current homes 1-5 years. The rest had lived in their homes for up to a year.

FIGURE 11 (N=104)



Panning out to community type, there are similar proportions of respondents in urban (36%) and suburban (36%) communities, and slightly fewer (27%) in rural communities (most of whom specified they were in small towns rather than remote or isolated rural areas). For this question, respondents were asked to choose from four descriptions to describe the type of community they lived in, and offered images of different densities of housing to assist them. They were also asked to select the amenities within walking distance of their homes (Figure 12). It should be noted here that “walking distance” was subjective—for respondents not accustomed to walking or not able to judge distances, the measure is highly subjective. There is good reason to assume, as discussed below, that these responses are entirely contingent on what the person answering the survey knows about the area around their home, and that is how the findings should be interpreted.

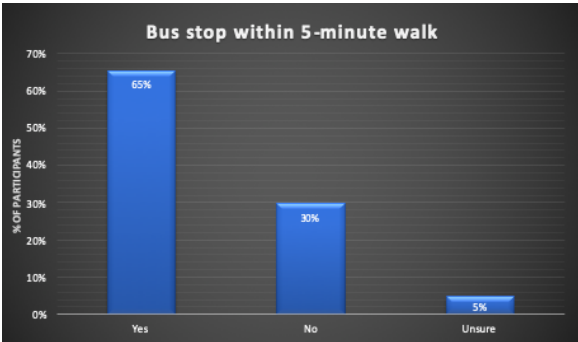
FIGURE 12 (N=104)



The most common amenity respondents said was within walking distance was a convenience store, reported by 59%. About half believed they could walk to a grocery store or pharmacy (52% and 50%). Fewer than 1/5 said they had a doctor’s office within walking distance, and around 1/10 could walk to their own workplace or a school. Smaller numbers said that parks, pet stores, libraries, and fast food were within walking distance. *Very* small numbers (1-2 respondents each) said they could walk to banks, walking trails and other amenities; these responses are not in the chart above. Given the distribution of such things as banks and trails in the urban communities where over 1/3 of respondents lived, it is likely that many respondents’ neighbourhoods contain amenities they are not aware of.

Respondents were asked specifically if there was a bus stop within a five-minute walk of their home, and nearly two thirds reported that there was one.

FIGURE 13 (N=104)



COMMUNITY AND HOME LIFE

The people who responded to this survey were asked a series of questions about their daily lives and experiences, to better understand what life is like in and around their homes. Picking up the last section’s theme of getting around and amenities, respondents were asked how often they use different modes of transportation to get where they need to go (i.e., appointments, errands, or visiting people). There is great variability in responses (Figure 14), but it is clear that respondents most frequently rely on a friend, relative or neighbour for transportation, with 38% saying they do this at least a few times a week. A slightly smaller proportion said the same about walking (36%) — but slightly more people said they walk at least once a day (15%) compared to any other kind of transportation (11% or less). Taking public transit was, again, slightly less popular, with 36% of respondents saying they never used it (compared to 29% who never walk and 19% who never rely on a friend, relative or neighbour). Taxis were very infrequently used.

These indicators suggest that respondents to the survey do not leave their homes very frequently. Indeed, just over one-quarter of the same (26%) selected “a few times a month” or less for *every* form of transportation. It is likely that the COVID-19 pandemic influenced these results; as many participants said they had activities and jobs that ended due to pandemic-related restrictions. Thus, leaving the house infrequently might be only a function of the pandemic. However, the findings suggest an avenue for future research into the everyday occupational (leisure, self-care, and productivity) lives of autistic and disabled adults in Nova Scotia.

Combined with findings from another question on social life and friendship, it is possible the pandemic is only part of the explanation for fairly stationary daily lives. Specifically, the survey asked respondents how many friends they had and saw regularly.

FIGURE 14 (N=104)

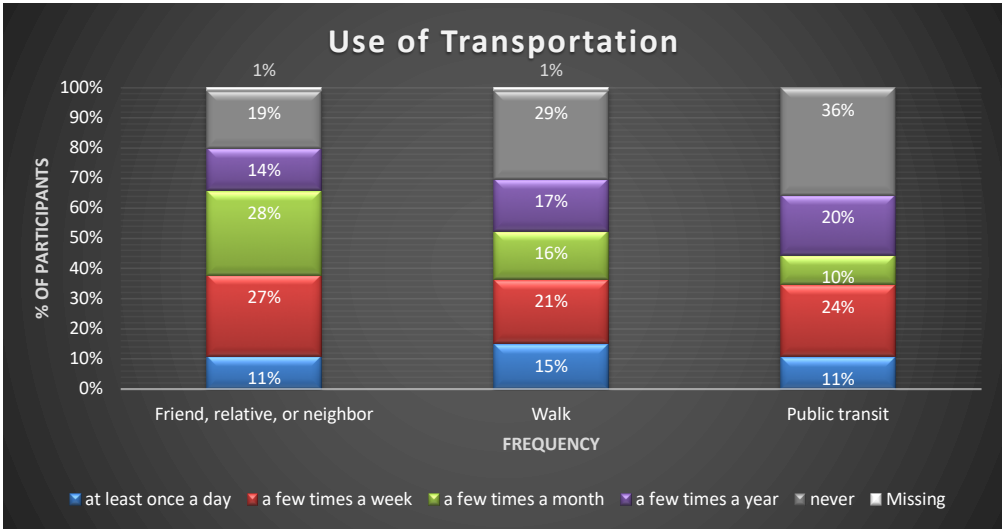
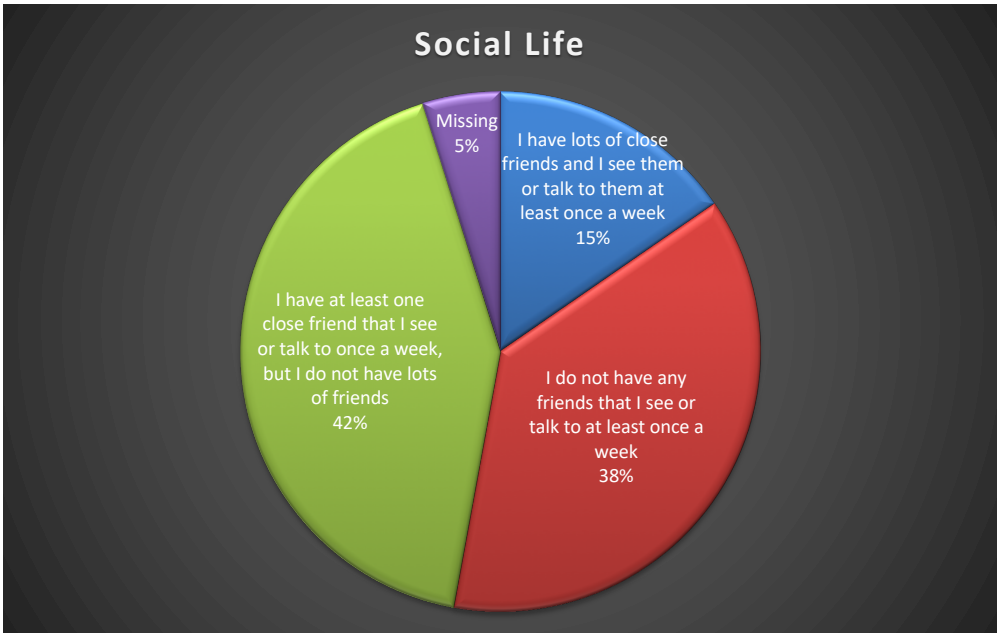
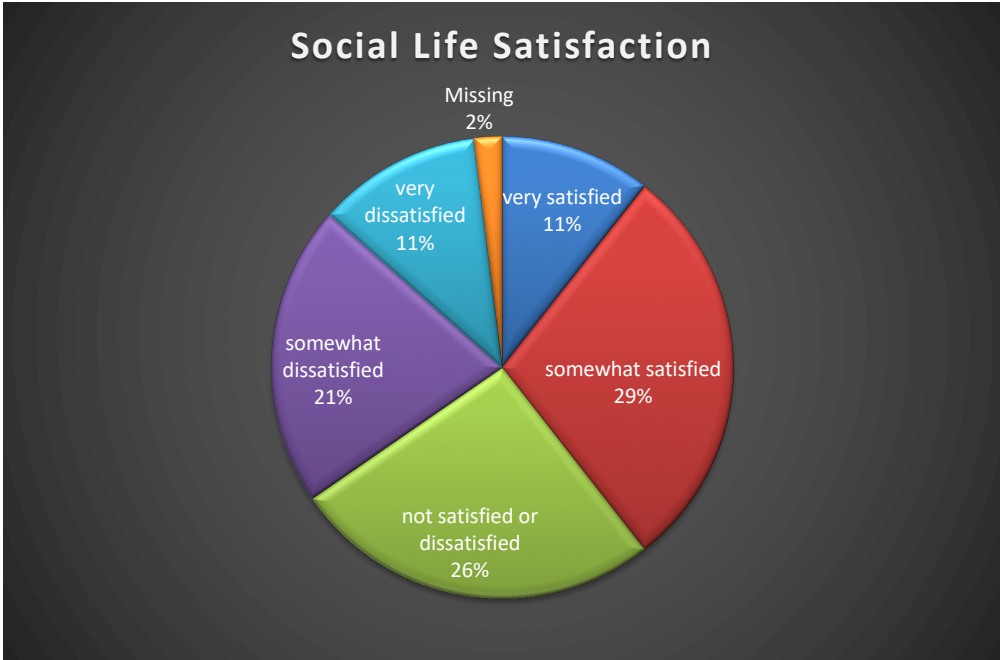


FIGURE 15 (N=104)



Forty-two percent of survey respondents said they have at least *one* close friend they connect with at least once a week (Figure 15). However, only 15% of survey respondents said they have *lots* of close friends and see or talk to them at least once a week, and a striking 38% said they do not have any close friends they connect with at least once a week. Immediately following this question, we also asked survey respondents how satisfied they are with their social lives (Figure 16).

FIGURE 16 (N=104)

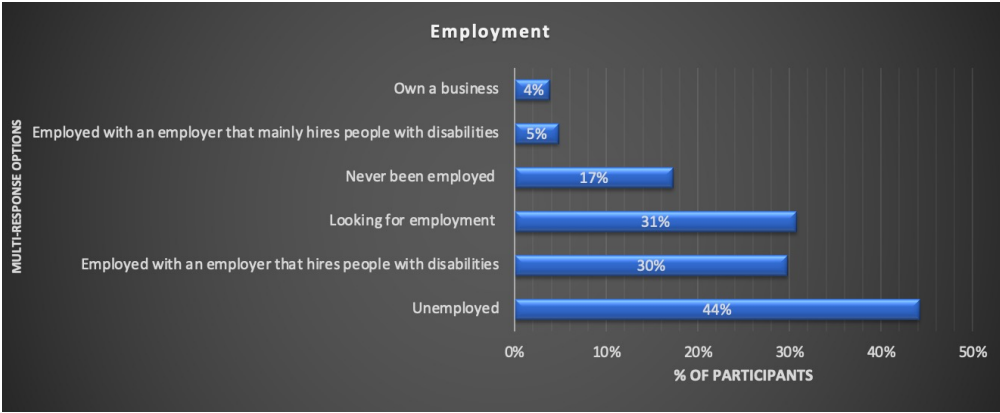


Just one in ten respondents (11%) said they are very satisfied with their social lives. The largest proportion (29%) said they are somewhat satisfied, followed by 26% who said they are neither satisfied nor dissatisfied — the neutral option. One in five (21%) are somewhat dissatisfied with their social lives. Bearing in mind that our sample is not representative, the results from this and the previous question still suggest that there are gaps in the social lives of a significant proportion of autistic people in Nova Scotia. Again, due to pandemic restrictions and literal social distancing requirements, this data may not accurately present the social lives and satisfaction of participants as autistic people, and may speak more to the impact of the pandemic on the social connectedness of all people regardless of neurotype, but they are worth attending to.

WORK AND INCOME

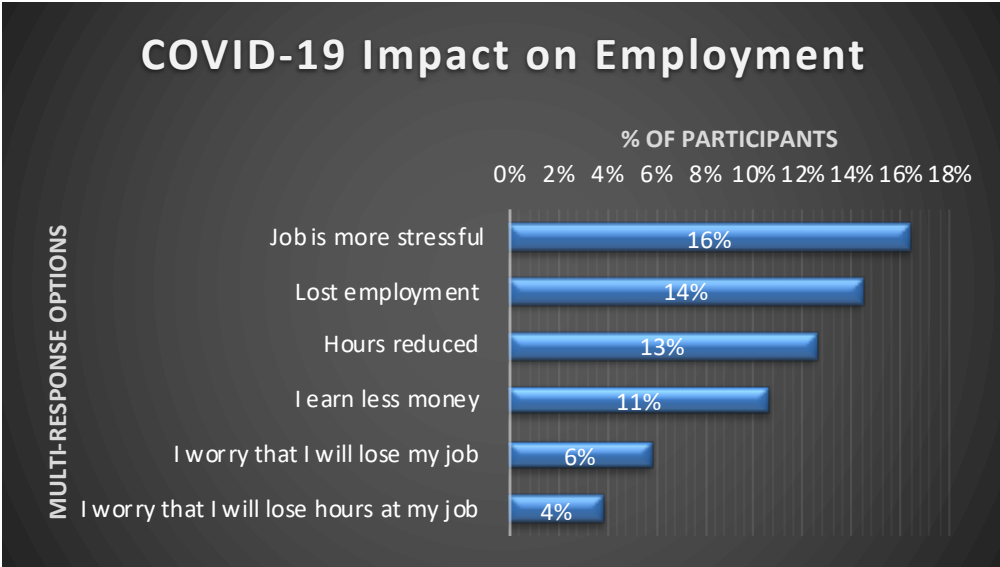
Given that — for better or worse — work occupies a central place in the lives of most adults, and the fact that autistic people tend to be underemployed, the survey posed a series of questions on employment. It also asked about income, given the contingency of housing possibilities on resources. As shown in Figure 17, nearly half (44%) of respondents were unemployed at the time of the survey. Not all unemployed respondents were looking for work — 31% of the entire sample said they were job-seeking.

FIGURE 17 | N=104



Slightly less than one in five respondents (17%) had never been employed. Thirty percent were employed at the time of the survey with a mainstream employer — that is, an employer that hires people with and without disabilities (e.g., a grocery store, movie theatre or university). Just 5% were working for an employer that mainly hires people with disabilities, and 4% owned their own business.

FIGURE 18 | N=86

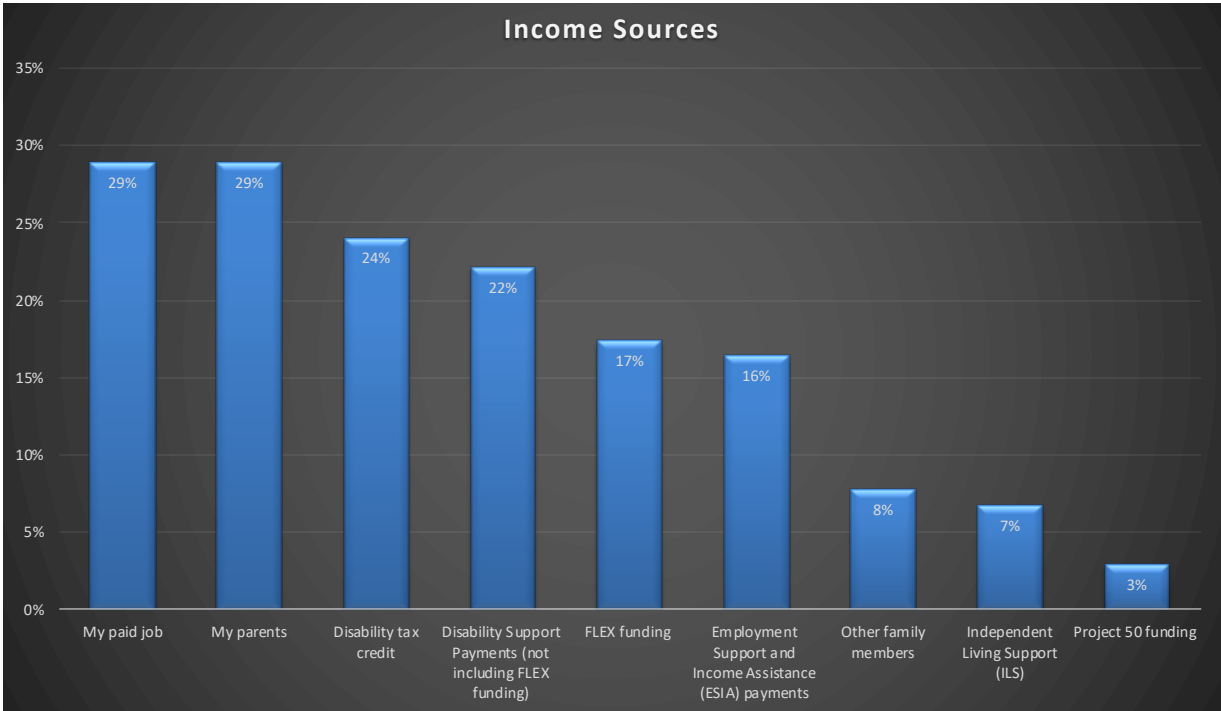


Fourteen percent of respondents (excluding those never employed) said they lost a job because of the COVID-19 pandemic (Figure 18). About the same proportion (13%) had their hours reduced. Sixteen percent said they had a job that became more stressful. One in ten (11%) earned less money as a result of the COVID-19 pandemic. Smaller proportions said they worried about losing their job (6%) or some of their hours (4%).

Employment was only one of many sources of income for respondents (Figure 19). Twenty-nine percent said they earned income from a job — slightly less than the proportion that reported being employed, as some respondents declined to answer the income question. The same proportion (29%) said they received income from their parents, and about one-quarter reported receiving the Disability Tax Credit

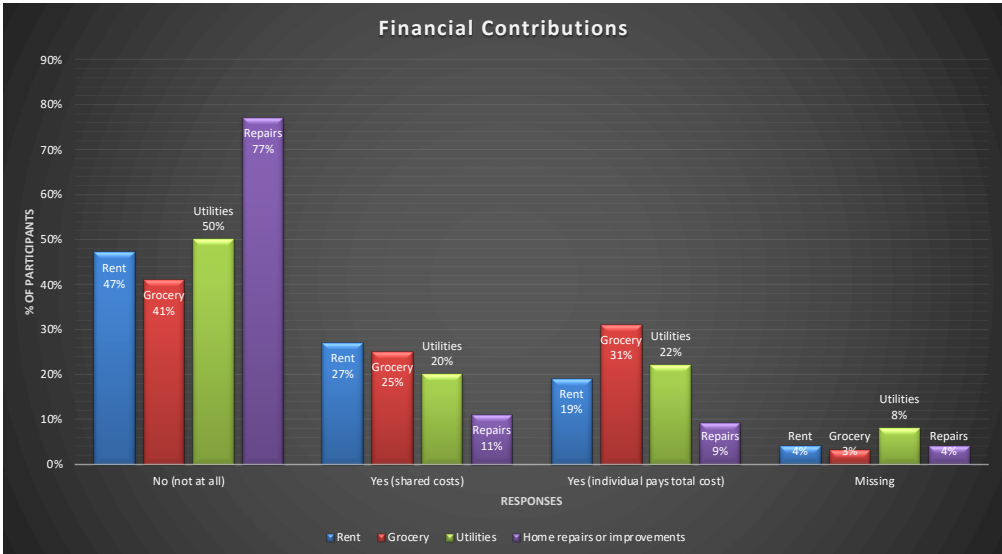
(24%), which exempts up to about \$5000–\$8500 of annual income from taxation, depending on the age of the person. One in five respondents (22%) reported receiving money from the Disability Support Program, a provincial program that provides recipients with modest monthly payments for shelter ranging from around \$500 to \$850 for a single person with no spouse or dependents. Seventeen percent (17%) said they received funding from Flex, a supplemental provincial program that provides funding for disability support needs beyond shelter and food; another 16% received income from Employment Support and Income Assistance (ESIA), which is the social assistance payment available to people with or without disabilities living on very low incomes. Smaller proportions reported income from family members other than parents (8%), Independent Living Support (ILS; 7%), or Project 50 funding (3%).

FIGURE 19 | N=104



Given the great variability in income sources and living arrangements, it is not surprising that there is also variation in respondents’ contributions to household expenses. As seen in Figure 20, respondents were most likely to say they did not contribute to rent (47%), groceries (41%), utilities (50%) or repairs (77%) at all. Just 19% of respondents pay their own rent, while 27% share rent costs with someone else. Thirty-one percent said they pay for all groceries, and one-quarter (25%) share grocery costs with someone else.

FIGURE 20 | N=104



One in five (22%) pay utility costs on their own (cable, internet, electricity etc.), and about the same proportion (20%) share bills with someone else. Only 9% of respondents said they pay for household repairs alone, while 11% share that cost with someone else. Given the small proportion of respondents who live outside the parental home, these findings are not surprising. It is also possible that some respondents' do not think of DSP, Flex or ILS as 'their own' income, and parents spend it without fully informing recipients how it is being spent. Nevertheless, findings do point to the increased expenses incurred by families whose adult children with disabilities live with them and are underemployed.

CONCLUSION

Spurred by international “community living” and “deinstitutionalization” movements, since 1996 the Nova Scotia government has overseen the closure of most large institutions where people with disabilities including autism used to live by default (Kendrick, 2001). Deinstitutionalization, alongside the shift toward person-centered approaches, has opened up the possibility of new opportunities for richer, more fulfilling, community living. But the old path to institutionalization has not yet been replaced with new, better paths that work well for all, or even most, people with disabilities (Kendrick, 2001). As our survey results show, a significant proportion of autistic people in Nova Scotia desire and expect to change where they live in the next five years, but for most, the path—even the next few steps—is not clear. Respondents say they need help finding suitable housing; this is where the largest gap exists between supports received and supports needed.

Suitable housing looks different for different survey respondents. More than half want to live alone, and about half say they are *able* to live independently without anyone checking in on them. Others would like to live with a spouse, children, or other family or friends. Very few would like to live with unrelated housemates. In other words, organic (or natural), relationship-based living arrangements are the desired ones for those who do not wish to live alone. Most people want to live in a detached home, but still significant proportions would be happy in an apartment building or flat. Above all, the desire is for privacy, safety, peace and quiet, but balanced with convenience. Respondents want to be able to get away and be alone, have control over their daily lives and activities, yet still have support and company when they want or need it. Some of the ignorance of (or disregard for) privacy in the creation and operation of housing for people with disabilities stems from the infantilization of disabled people and the assumption that they do not need or have a right to privacy because they do not (or should not) be engaging in private acts such as sex or masturbation—acts that *all people* can engage in and deserve private space in which to do so.¹⁰

Our brief scan of the different housing and support models in existence around the world tells us it is *possible* for a balance of private and social space to be built into group homes, but respondents understandably associate values such as privacy and quiet with detached houses and living alone, because the typical, non-person-centred group home probably does not offer the level of privacy and quiet residents would prefer. Thankfully, more detached, single- or double-occupancy living situations have been shown to be possible—the key is person-centered approaches, with supports that are customizable and attached to the person rather than the house.

At the time of the survey, there were low levels of satisfaction with social lives and friendships, and worryingly low levels of employment and income. There appear to be low levels of mobility and activity in general, with very small proportions reporting leaving their homes for errands and other types of outings. Moreover, just under one third of respondents make money from employment. Given the housing market context in Nova Scotia in 2021—with historic highs in homelessness, skyrocketing rents and a rental housing shortage—the prospects for people with disabilities, who tend to need supports to live in community and tend to lack resources to fund it themselves, are very poor.

¹⁰ <https://www.theatlantic.com/health/archive/2015/03/sex-and-disability/386866/>

The idea that autistic people can and should live in communities, be integrated fully into the social and cultural milieu as well as physical spaces of those communities, make choices about housing and lifestyle—the central tenet of “community living”—has been normalized in Nova Scotia and around the Global North. But again, many international scholars and community advocates assessing the transition from deinstitutionalization toward true “community living” in their jurisdictions argue that it is characterized by “unrealized” promises (McCauley & Matheson, 2016) for autistic people or those with any kind of disability (cf. Kendrick, 2001).

In short, across the developed world, wherever institutional living has dissolved and community living has become the goal, the remaining patchwork of family, community, private sector, government and non-profit supports has not coalesced into anything sustainable, let alone easy for families to navigate (Friedman et. al., 2013). The people who responded to our survey get by with whatever they can access from the patchwork, but there were substantial unmet needs, both in terms of the bricks and mortar of housing, and in terms of the social supports with relationships, employment, school and staying organized.

Our survey shows that most autistic people need some kind of support, but for a large proportion, the support needs are modest. The fact that there are people who are under- or inappropriately supported (for example, living with their parents long into adulthood) reflects what many other researchers have found: a mismatch between the housing options people want and those they have access to; this mismatch is costly, to families, governments and entire societies (Autism Nova Scotia, 2017; Buescher et. al., 2014). The solutions advocated by Autism NS and other disability-focused organizations make sense given the findings from this survey: governments need to create new housing options, invest in more community living supports, and continue to deinstitutionalize existing arrangements. Much could also be achieved by creating greater efficiency and coordination among disparate service providers to help keep costs lower. Above all else, it is imperative to continue the move toward person-centered, individualized supports, as this is the best way to ensure better, fuller lives for people of all abilities, and it is ultimately what many, if not most people with disabilities want in housing, and more importantly, in a *home*.

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APPENDIX 1

GAP BETWEEN NEEDED AND RECEIVED SUPPORTS (ALTERNATIVE FORMAT)

