Reviewing the Evidence for Supported Housing and ASD

Prepared for: Autism Nova Scotia

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ACRONYMS

ASD	Autism Spectrum Disorder
AFSP	Alternative Family Support Program
DCS	(Nova Scotia) Department of Community Services
DHW	(Nova Scotia) Department of Health and Wellness
DSP	Disability Support Program
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
SES	socio-economic status
WHO	World Health Organization

EXECUTIVE SUMMARY

Autism Nova Scotia's (AutismNS) 2016 report, *Choosing Now*, identified supports in housing as among the most pressing issue confronting adults with ASD and their families in Nova Scotia. In the 1990's, Nova Scotia was at the forefront of Canadian reform, closing institutions and developing community-based small-option homes that were models for the rest of the country. However, despite this early movement, significant challenges have developed: most notably a long waiting list for community-based housing options, limited resources to create more housing, and a struggle to create sustainable support-structures, early in life, that can follow through to the transition from the family home to community-based living. With the low number of new housing developments, and growing numbers of youth and adults needing homes, it is important to lay the groundwork for innovative housing solutions and action.

Many reports have been published over the last thirty years describing the issues around housing for individuals with a disability in Nova Scotia. These reports consistently identify what is needed for housing and some focus on the essential societal and family values, necessary supports for living independently, and recommendations for system change. Most of these reports draw on family, professional, and expert opinion while acknowledging that one size does not fit all, none have focused on the unique needs of adults with ASD, and few have reviewed evidence-based practices that need to be implemented in the operations of home-based and residential support services.

This report provides a review of the evidence base to support decision-making for developing housing options. Specifically, it outlines the recent research on Youth with ASD transitioning to adulthood, the appropriate supports for individuals living at home who will eventually transition to supported community living and views the in-home-supports and transition through the lens of quality of life—highlighting what fundamental elements are necessary for youth and those transitioning to adulthood, to create a wraparound system that functions across housing models. This will provide us with foundational knowledge for thinking about how housing and supports services can be spread across the province to best respond to the growing ASD population's range of personal, community, and service needs.

Ensuring access and support is a critical part of an effective housing strategy, and this starts early in life with the establishment of basic support tactics and strategies that grow with an individual, adapting to the alignment of support they receive from family, professionals and the wider community. The research underscores the importance of aiming for a good quality of life, using a combination of evidence-based practices such as person-centered transition planning, environmental accommodations, and positive behavioural supports. Successful transitions and leading a quality life are only possible when there is a range of transparent options and opportunities for living in the community. In Nova Scotia, self-advocates, along with the support of their family members, 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 for individuals with ASD, like all developmental disabilities, requires meaningful community options, and economically viable social policies are urgently needed.

Terminology

Throughout this document you will see the term Autism Spectrum Disorder (ASD), and how it applies to individuals, referenced in a number of ways. Language within the Autism community is evolving as more is understood about the condition and how it impacts individuals and the lives they lead. 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 these different representations throughout this paper, in the hopes that our members can all relate, and see themselves within this report.

There are some terms that the community is pushing to move away from — such as “high functioning” and “low functioning”. How well individuals can function has long been qualified or measured as correlative to heir ability to use verbal language and IQ levels. This not only places unfair assumptions about individuals who are non-verbal, or those who have learning disabilities — it also creates systemic barriers, for Autistic individuals who may have high IQs but face significant challenges, for example, with social communication and problem-solving skills. As one 2016 article posited;

> …being tagged as high-functioning can have unfortunate consequences. Any person, regardless of whether they have autism, functions better in some areas of life than in others, whether that’s making and keeping friends, learning and remembering information, taking care of themselves, communicating, solving problems or paying attention. Saying a person with autism is high-functioning implies they are competent in all of these areas, but that’s simply not true...In practical terms, either label can be limiting: It might prevent one child from participating in activities she wants to do, or exclude another from getting the services he needs”[1]

The references to functioning levels are only used in this document when directly part of sourced information. At all other times, we do our best to avoid these terms because they do not adequately reflect the great attributes and significant challenges faced by individuals on the autism spectrum.

This reports usage of the term “in-home supports” throughout is meant to communicate exactly that, supports in the home. Importantly, home can mean different things for people in different circumstances. While the vast majority of persons receiving in-home supports are doing so in a “family home,” often out of necessity because viable community based housing is scarce, it is important to also recognize that many people are in “community based” housing, away from family, for a variety of reasons. When we refer to the practices, ideals or the idea of in-home supports, we are referring to any housing arrangement, particularly in the child and youth population, that is a home for the person. While some distinctions are made between those provided to the Child and Youth versus Adult populations, the usage of in-home supports places the desires and needs of the person at the centre of the conversation—making it imperative that the individual understand the site of support as a home, with all of associated quality of life benefits of living in a home, rather than an institution.

Definitions

Neurodevelopmental Disorders (NDs) are a group of disorders in which the impaired growth and development of the brain and central nervous system affects emotion, learning, self-control and memory. NDs include autism spectrum disorder, intellectual disabilities (Intellectual Developmental Disorder), communication disorders, attention deficit hyperactivity disorder, and Tourette’s disorder.[23]

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 behavior 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.

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, or muscular dystrophy).

Autism spectrum disorder, intellectual disability, and developmental disability do co-occur. This co-occurrence adds to the complexity of individuals' experiences of daily challenges and of course, to the complexity of the solutions they need to lead a fulfilling life. In contrast, people who experienced typical development, growing up and struggling with none of these challenges, are called neurotypical by the autism community (see the definition below).

Neurotypical (NT)[3] is "used either as an adjective or a noun refers to people who do not have autistic-type brains. NT is considered more specific than 'normal', as the definition of "normal" is very much dependent on context. However, members of the… [ASD] community are well aware that within the context of humans-in-general, we are not normal. It is not considered insensitive or pejorative to acknowledge this fact. Most of us don't mind not being normal and would not want to be normal. We appreciate being acknowledged for what we are."[4]

BACKGROUND AND INTRODUCTION

Autism Spectrum Disorder (ASD) is the most common neurological condition diagnosed in children (1 in 68).[5] The needs of autistic individuals require varying amounts of individualized support across the lifespan. One major issue confronting children and adults with ASD in Nova Scotia is access to appropriate, adequate supports in their living environments; such supports are a foundation for more inclusive, community living. For a growing number of Nova Scotians with ASD, there is a historical and current lack of ASD appropriate supports and individualized options for those transitioning away from the family home.[6]

Evidence shows that in cases where home or community-based support is unavailable or inappropriate, the human and social costs grow and become exponentially higher as they are pushed out into the health and social service landscape.[7] Support at home, be it through adequate in-home supports, supported-living models, or outreach health and behavioural services, is the foundation of stability required to achieve success in other areas of life such as employment, education, and personal development. The magnitude of the crisis created by inadequate, maladapted support systems for persons with ASD cannot be overstated.[8] Without viable support options around housing and in peoples' homes, the autistic population of Nova Scotia faces a higher risk of developing even more complex needs and interventions. All of which cost individuals with ASD, their families, the Departments of Education and Community Services, Justice, and the Nova Scotia Health Authority more in the short- and long-term.[7]

Unfortunately, there are no simple or easy solutions that will meet the current housing needs for all people with ASD. Primarily because there is a variation in need among people with ASD spanning from complex, 24/7 care delivered in-home or in residential environments, to crisis stabilization housing needs, to less intense support needs.[9,10] Moreover, the nature of these supports may vary significantly based on age, stage, and family resources. For example, while some individuals may need the expertise of clinicians and coordinated supports within the family home, some may need to relocate into a stabilization service for treatment, while other individuals may have home environments where only respite or minimal assistance is required. Moreover, these needs shift with age and stage of the life course, as autistic youth or adults, along with their family members, want to start transitioning to a supported housing environment beyond the family home. Taken together, this means that supportive housing and home model solutions must reflect a broad range of needs by offering a variety of solutions that persons with ASD and their families can choose from or help develop with support from service providers and other stakeholders.

The Challenge

Autism NS's Choosing Now report identified housing as a pressing issue for adults with ASD and their aging parents in Nova Scotia.[11] In the 1990s, Nova Scotia was at the forefront of most provinces in Canada by closing institutions and developing community-based small-option homes.[12,13] Despite this early momentum, significant challenges still exist, most notably a long waiting-list for community-based housing options and limited resources to create more. Now that housing developments have stalled, and growing numbers of youth and adults with ASD will need homes now, and in the future, it is important to lay the groundwork for innovative housing solutions and action.

Many reports have been published over the last twenty years describing the issues surrounding housing for individuals with a disability in Nova Scotia.[12,13,14] None of them have focused on the unique needs of adults with ASD, and few have reviewed evidence-based practices to inform decision-making. This report will provide a review of the evidence base to support decision making for developing housing options for adults with ASD. Specifically, it identifies the recent research on the transition to adulthood, what is needed to experience a good quality of life as an adult with ASD living in or outside of their family's home, housing models, and wraparound systems of support and care.

ASD is….

ASD is a neurodevelopmental disorder that manifests as impairments in communication, social interactions, and processing sensory information, combined with restricted and repetitive behaviours, interests or activities.[2] ASD is typically identified in early childhood, with males diagnosed four to five times more frequently than females.[5] Each person with ASD is unique and will have different abilities, symptoms, and deficits. This condition is named a "spectrum" disorder because the range of abilities and deficits can fall anywhere across a spectrum, and support needs may range from none to very substantial. It is a complex, life-long condition.

In Nova Scotia (NS) and elsewhere in Canada, the diagnosis of ASD is usually provided by medical doctors, psychologists, or psychiatrists, who typically use direct observation of behaviour, developmental interviews, and standardized assessment tools based on criteria from the Diagnostic and Statistical Manual of Mental Disorders (i.e., DSM-5)[2]. The number of people diagnosed with ASD has been increasing over the last few decades.[15] This is due to better awareness of the signs and symptoms, a clearer definition of ASD, more accurate diagnostic tools, and many children and adults who were previously diagnosed with intellectual disabilities are now diagnosed with ASD.[15]

Prevalence of ASD in NS: Estimates for Community-based Residential Options

According to a recent report by the Public Health Agency of Canada (PHAC), the prevalence rate of ASD in Canada is one in 66 children and youth (i.e., based on data of 5 to 17-year-olds in 2015, from six provinces and one territory), and in Nova Scotia, it is one in 68.[5] While some children may receive a diagnosis as early as two or three years of age in NS, PHAC reports, five-year-olds were the most frequently diagnosed in 2015.[5] At least 72% of children diagnosed received their diagnosis by eight years of age, and the vast majority (90%) received their diagnosis before the age of 12.[5]

An estimated 7,832 people with ASD live in NS (see Appendix A for a more detailed explanation). Because the focus of this report is transition planning for community-based housing options, this calculation was applied to the number of youths, young adults, and older adults with ASD living in NS who are either transitioning to adult life or currently seeking housing options. The estimate for the province suggests that there are 451 youth, ages 15 to 19 years old, 500 emerging adults, ages 20 to 24 years old, 509 young adults, ages 25 to 29 years old, and 1029 adults, ages 30 to 39 years old. While these projected estimates of prevalence must be interpreted with caution and should only be used as possible estimates, it suggests that in Nova Scotia, as many as 451 youth with ASD will be transitioning to adulthood in the next five years and over two thousand adults are currently or soon will be seeking community-based residential options (please note this estimate is based on the evidence that very few residential options have been created over the last 20 years in Nova Scotia: see Appendix B).

> *"AutismNS believes that any strategy to promote community living and address the housing needs of adults with ASD must focus on developing an adequate supply of a range of different housing options, located and distributed according to community need, so that people with ASD and their families across the province can truly and freely choose the living arrangement and level of support that works for them."*[11]

Overview of the Report

The overarching intention of this report is to provide an overview of the evidence on what is possible, what is needed, and what works for individuals with ASD as they transition to community-based residential living, receiving in-home supports from Childhood to Adulthood.

The report is divided into four sections. The first outlines the evidence on the characteristics of ASD, youth and adult outcomes. It also reviews how quality of life is emerging as strong framework, especially when it is used in conjunction with person-directed transition planning. The second section, based on person-directed transition planning (i.e., the values and goals of what people want and need in their lives), focuses on the best practice supports that will help adults with ASD to live a good quality of life wherever they choose to live. The third section provides the current evidence on "bricks and mortar" adaptations that create "ASD friendly" functional and structural environments. The fourth and final section of this report will detail the positive behavioural wraparound support that will promote QOL goals, positive support, functional and structural housing considerations, and welcoming places at home and in the community for people with ASD.

1. Quality of Life (QOL) on the autism spectrum
2. Transition Planning for QOL with Positive Support
3. ASD at Home and in the Community
4. Positive Behavioural Wraparound Support

Since a key use of this report is for decision-making, only the main findings will be drawn from the research in these areas of study (i.e., a technical document with more detail on sample sizes and methods is available by request). The literature review search methodology is described in Appendix C.

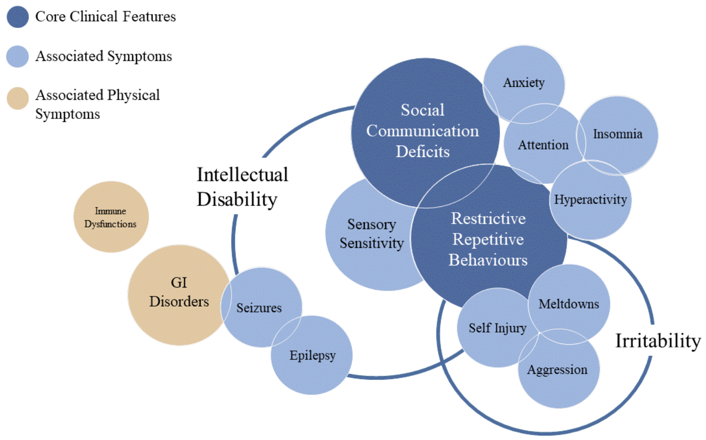
PART 1: Quality of Life (QOL) for Youth and Adults on the Spectrum

Living Life with ASD: The Complexities That Shape Supports-at-Home and Housing Need

A critical aspect of planning for a quality of life with individuals and their families is considering the spectrum of abilities and the constellation of difficulties that are associated with and can occur with ASD. Many children, youth, and adults with ASD are also diagnosed with co-existing physical, mental, and behavioural health conditions. The research on individuals with ASD and the impact of these challenges is well-established.

Co-occurring Physical, Developmental, and Mental Health conditions

Figure 1: ASD core clinical features and associated neurological and physical conditions



Individuals with ASD commonly have one or more other cooccurring conditions (see Figure 1).[16,17] Across the lifespan, people with ASD have higher rates of nearly all major medical and psychiatric disorders than those reported in the general adult population.[18] It is associated with other developmental disorders (e.g., Attention Deficit/Hyperactivity Disorder, language disorders, intellectual disability, sensory integration disorder). It is also common to find a co-occurrence with mental health, neurological, sleep and gastrointestinal disorders (e.g., depression, anxiety disorder, obsessive-compulsive disorder, Tourette syndrome, seizures or epilepsy, insomnia, acid reflux, indigestion, and constipation).[16,17] These health problems are found in all age groups, and conditions can often worsen as individuals age, particularly without proper management and support earlier in life, which partly accounts for the shortened average life expectancy among people with ASD.[19,20] Evidence from a large-scale population study conducted in Sweden found the average life expectancy for an adult with ASD was 54 years. People with ASD and intellectual disabilities had an average life expectancy of just under 40 years.[19,20]

Behavioural Challenges

Across the lifespan, individuals with ASD as well as an intellectual disability are also more likely to experience co-occurring behavioural challenges.[21,22] Behaviour is widely understood as challenging when it is intense, frequent, and interferes with daily life, preventing an individual from learning and developing, and/or threatens personal safety or the safety of others. These behaviours include aggression, self-harming, disruptive behaviour, and continuous stereotypy.[22] The prevalence estimates of these behaviours in individuals with ASD, and those with ASD and a co-occurring intellectual disability, are consistently and significantly higher than estimates for individuals diagnosed with intellectual disability alone.[21–24]

Sensory Processing and Sensitivities

ASD has also been associated with atypical sensory processing. [25] The most recent version of the DSM has included sensory processing dysfunction (e.g., hyper- and hypo-reactions to sensory information) as a key component of diagnosing ASD.[2] Atypical sensory processing interferes with daily functioning and is linked to behavioural difficulties as well as health concerns. One review of 66 studies assessing sensory processing in ASD found it was related to behavioural problems, gastrointestinal (GI) problems, eating disorders, sleep issues, anxiety, parental stress, and family impairment.[26] These reports of sensory difficulties are found in all ages across the spectrum,[26] adding another layer of complexity to the social communication and behavioural profiles of ASD, which in turn also create particular necessities around appropriately accommodated housing and in-home supports.

Implications for In-Home Supports and Housing Policy and Models

The greater risk of experiencing sensory, behavioural, developmental, and mental and physical health difficulties creates stress and challenges in many aspects of life - especially in developing daily living skills, social skills, and more. Importantly, these individual challenges create larger social problems: cumulatively, they stress the mechanisms for supporting people in family or supervised homes, and make the move to community-based, independent living more complex. Simply put, ASD and the constellation of co-occurring conditions, which vary from person to person, undermine the ability of any policy and practice to offer a single option solution. Thus, the evidence suggests utilizing a framework with a menu of options that can be flexibly individualized.

ASD Outcomes and Living a Quality Life

Leading experts on adult ASD outcomes and community-based services are shifting the focus from outcomes associated with the reduction of ASD symptoms to quality of life[*] outcomes.[27–31,32] In practice, researchers and service providers, are displacing outcome foci that are overly and narrowly focused on overcoming the symptoms of ASD and comparing the outcomes for people with ASD relative to the outcomes one might expect for neurotypical adults.[33–42] Those foci, by design, always found the lives of individuals with ASD wanting, and failed to account for the importance of people’s subjective understandings of their own lives.[43,44,32] As a result, research attention has expanded from normative adult outcomes (e.g., independent living) to include objective QOL outcomes (e.g., residential quality) and subjective QOL outcomes (e.g., liking where you live).[43]

QOL and ASD-Friendly Environments

Measures of QOL for adults with ASD assess the quality of support they receive, where they live and their environmental conditions, if they have individualized plans, and the quality of their daily routines.[28,38,45,46] To date, the overall findings suggest there is a need to address how outcomes and QOL are defined and conceptualized for people across the spectrum.[9,27,45] To accurately assess and measure general outcomes and QOL outcomes, researchers consistently iterate how important it is to better understand what people with ASD “value”

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[*] 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]

and what "good" QOL means to them.[9,27,45] Collectively, they urge others to expand on current measures to assess what individuals with ASD value in their lives and whether they believe their environment is a good fit and provides them with what they need to live a good life.[9,27,45,46] Researchers recommend ASD-specific QOL measures, designed for people across the spectrum, capturing the extent to which individuals experience an "autism-friendly environment" as a more appropriate measure than those developed for the general population.[45,46] Robertson (2010), a self-advocate with ASD and a researcher, has recommended Schalock's conceptualization of QOL, because it is built on rights-based values and promoting well-being as foundational to QOL.

Quality of Life Framework

When tasked with how to outline ideal supports in housing and housing models, our review of the research led us to the work of Schalock and his colleagues. Over the last three decades, this group of researchers and practitioners have explored personal, organization, and societal practices and values, that when practiced daily, lead to better outcomes and QOL for people with intellectual disability. These include eight QOL domains (i.e., self-determination, personal development, emotional well-being, physical well-being, material well-being, interpersonal relations, social inclusion, and rights).[47] These domains were furthered refined into three core outcomes (i.e., independence, personal well-being, and social participation).[48] It was then expanded into a Quality of Life Framework and a model for practice.[31] The model includes strategies that promote QOL in each domain, a validated QOL questionnaire which is designed with questions for people with intellectual disabilities and/or the person who knows them best, and indicators to evaluate personal and organizational outcomes (see Table 2).[31,49]

Table 2: Quality of Life Framework

QOL Domains	**QOL Outcomes**	**QOL Strategies**	**QOL Indicators**
Self-determination	Independence	Person-directed planning	Choices/decisions, autonomy, personal control, personal goals
Personal development		Individualized support Assistive Tech • Communication Tech • Sensory-motor devices Environmental Accommodations Incentives Skills/knowledge Positive Behavioural supports Health Services: IT, OT, PT, speech, medical, psychiatric, psychological Employment Support	Education status, personal skills, adaptive behaviour, ADLs, IADLs
Emotional well-being	Personal Well-being		Safety and security, positive experiences, contentment, self-concept, lack of stress
Physical well-being			Health status, nutritional status, recreation/physical exertion
Material well-being			Financial status, employment status, housing status, possessions
Interpersonal relations	Social Participation	Personal Growth Opportunities	Social networks, friendships, social, activities, relationships

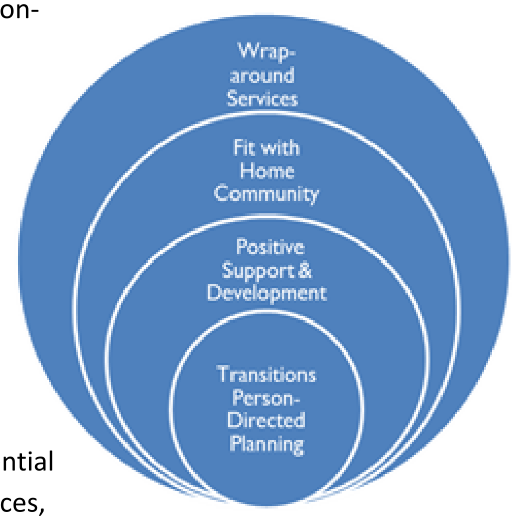
Social Inclusion		Involvement with a meaningful role in community life	Community integration/participation, community roles
Rights		Policy and Advocacy	Human (respect, dignity, equality), Legal (legal access, due process)

This framework offers the most robust and evidence-based system with which to define quality of life as multi-dimensional, that adheres to the UN Convention on the Rights of Persons with Disabilities[50], while also helpful in in assessing the efficacy of various in-home supports and supported housing models. Importantly, this QOL framework provides a framework that can help create clear points of accountability for funders and service providers, possessing an evaluation framework, that can inform and influence support strategies and environmental factors, service provision and policy to have a positive impact on quality of life-related outcomes.[51]

Importantly, this framework also helps shift the approach to in-home supports and supports around housing generally, from a "care" model—wherein people are seen as needing to be cared for, to a rights-based model--wherein people have a right to direct their own lives and be included in the community with the supports they need.[52,53] This model has been empirically validated across different cultures and countries[48,49,51] (please see Appendix E for jurisdictions who have used this model).

Implications: QOL Framework for In-Home Supports, Housing Policy and Models

Jurisdictions who use this model and framework (e.g., Canada, Australia, Ireland, Spain) use various QOL survey tools[*] and processes tailored to meet the wants and needs of service users, providers, and the larger ecosystem. Results from person-directed QOL surveys ripple out to inform standards, quality initiatives, service outcomes, and finally, culminate into QOL population-level outcomes, which help direct resources to the most effectual housing models and services. There are multiple benefits from organizations having the same conceptual and measurement framework to share information, learn from one another, develop partnerships, revise organizational approaches to service delivery and quality improvement, and provide information to other organizations throughout a community.[54] Reports on aggregated QOL outcomes are not only used to inform residential services but other necessary services (e.g., employment services,



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[*] see the Outcomes for Disability Services for a review of QOL Measures, National Disability Authority, May 2016

health services, recreational services). The QOL concept can be assessed and applied at all levels: 1) development and delivery of program and services, 2) effectiveness of program and service outcomes, and 3) impacts on individuals, organizations, and systems.[52] This aligns and integrates a range of programs and policies to have a broader and deeper impact on the lives of people with ASD and other disabilities.

This QOL methodology and framework is particularly relevant for residential services that work with people with ASD, because it can be individualized to accommodate the complexity of ASD. Good outcomes within a QOL framework require an individualized approach that is directed by the person with ASD and their family. Although providing positive behavioural support is an integral ingredient for better outcomes (see Part 2 of this paper), a person-directed planning process first identifies QOL goals - what people want in their lives, desired and necessary outcomes—so that positive support strategies flow out of the goals set around an individuals personal development. This flips the current in-home and residential care model in many instances, so that the focus on interventions flows from goals, building "wrap-around" supports and services that integrate person-directed planning with positive support for an optimal "fit" with daily activities, home life, and meaningful participation in the community. When all of these elements are working together, this model plays a significant role in promoting QOL for youth and adults with ASD.

The next sections of this report will discuss how to tailor this model to our local context around the question of in-home supports and housing models. The values and processes which are inherent in the QOL model (e.g., self-advocacy and person-directed planning) become especially important when parents and youth with ASD transition into adulthood and consider being more independent in the community or moving from their families' home or to a home of their own.

PART 2: Transition Planning for QOL with Positive Support

Transition planning: Barriers and Person-centered Planning

The transition to adulthood is a vulnerable time for all youth and their families, but it is especially fraught for youth on the autism spectrum.[55] Youth with ASD continue to experience issues with communication, social skills, behavioral challenges, planning and decision-making, and co-occurring mental health problems, with the added expectation of moving into adult life.[55]

Transition Planning for QOL with Positive Support

Studies of Canadian parents of children and youth with ASD show that parents share deep concern for their loved ones as they the transition from school into adulthood.[56] Specifically, most worry about shifting from the child and adolescent services landscape, to an adult system where resources are more scarce and more difficult to navigate.[57] Common challenges that emerge include differences in eligibility criteria, vetting and trusting new service providers, navigating long wait-lists, and trying to tailor services designed for the robust categorization of developmental disability, that structures the delivery and availability of services and funding, to the complex needs of ASD. This can be especially difficult for youth with ASD without a co-occurring intellectual disability. This is because, despite communication and social skills commonly and significantly impacting ability to socialize, navigate systems, or hold a job, persons on the spectrum may be ineligible for adequate supports or lack access to appropriate services. Families commonly and frequently struggle to navigate these transitions, often going without services and supports, which can significantly impact both the individuals development and integration, as well as affecting theirs and their families earnings and well-being.[56,57,58]

There is very little research or evidence on what works during transitions from school-age to adulthood for youth with ASD, even though it continues to be a major issue and the life stages of adolescence and emergent adulthood are a critical period of growth and development for individuals with ASD. It follows that there is little research on the transition from a family home, or one community based living arrangement, to another community based living arrangement.[59,60] Studies have revealed a gap in support services for young adults transitioning to independent living, integrated employment, and community participation as a whole,.[59] This results in overall higher rates of social isolation, an observable deterioration of familial relations, and increased likelihood of compounding mental health issues—with disparities by race, socio-economic status, co-occurring mental health conditions. [57] While some studies have detailed the development of behaviour intervention plans for transition-age adults (e.g., Schall, 2010[61]; Schall et al., 2012[62]), there have been no studies evaluating the effectiveness of these plans within, or as part of a transition to, community-based settings. Experts recommended more research on how to develop self-determination, self-advocacy, goal setting skills in youth with ASD, with an emphasis that it should be a priority for youth to participate in any planning for transitions to adult life.[63,64,65]

This point of participation is particularly important because studies on transition planning have shown that youth and young people with ASD were less likely to participate in transition planning meetings than other groups of youth with disabilities. They also found that youth with ASD were less likely than youth with other disabilities to have transition goals for college or vocational training or for competitive employment or living independently. However, they were more likely to have transition goals for supported employment, maximizing functional independence, enhancing social relationships, and self-managing behavioural difficulties. The researchers noted that a lack of youth with ASD participating in transition planning is concerning, because participating, choosing interests, self-expression, and having control over one’s goals in life is foundational for developing a sense of agency and ownership of the plan.[66] Broadly, in the transition planning for youth with ASD, there is also a noticeable lack of focus on planning for supported residential options which may account for how ill-prepared parents feel when their children leave high school.[67]

QOL Transition Planning: What is Person-Centered Planning

Person-centered planning (PCP) is a flexible and widely used approach for planning. So much so, there is no one definition of person-centered planning and at least 9 different person-centered approaches (for a review, see O'Brien, 2013). However, the philosophy that connects all of these approaches is that the focus should be on the person and what they want versus a focus on what the system can provide—born out of a need to support people with disabilities moving out of large facilities and into community homes.[68,69] Person-centered planning is, therefore, both a process and an outcome. It can be used to create plans for all aspects of life and facilitate change for individuals, programs, services, and systems.[68]

Studies have shown that person-centered planning can be an effective tool in multiple types of functional plans. For example, when developing positive behavior support plans in combination with person-centered planning, independent living and career plans, innovative and culturally responsive person-centered planning, later-life planning, life-span planning, and all-purpose planning for the future.[70] Collectively, studies have found that person-centered planning results in moderate change and/or effectiveness for improving social networks, community involvement, choice-making, knowledge, and reducing challenging behaviour. One particularly strong study reported significant outcomes with a group of adults with challenging behaviour who had been living in an institution since they were children.[69] Person-centered planning resulted in 18 out of 19 participants moving to community based living with more successful transitions than those who were in the control group with no person-centered planning process (without person-centered planning 5 out of 18 transitioned).[69] Person-centered planning was found to be an emancipating process, in that it involved individuals and their family members in developing a "larger vision" for what was possible when their lives had been limited by institutional practices.

ASD-specific Person-centered Planning

ASD specific Person-centred Planning is emerging in the research literature and evidence shows that three key factors contribute to a successful planning process[71]:

1. An individualized and strengths-focused approach that provides choice and flexibility with support for visualizing and making concepts concrete (i.e., predisposing factors).
2. Skill development and guidance using real-life experiences (i.e., reinforcing factors).
3. A coordinated approach with a clear plan, scheduled meetings, and formal documentation (i.e., enabling factors).[71*]

The Collaborative Model for Promoting Competence and Success (COMPASS) is an effective evidence-based transition planning practice that supports students with ASD through a planning process with their family members. The COMPASS process takes an individualized

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[*] These factors informed the development of the BOOST-A™ online transition planning tool for youth with ASD.[164] For more details see Appendix E.

and holistic approach to identifying educational, employment, support, and housing, as well as life-style goals. Given the breadth of abilities across the spectrum, processes must be adaptable and shift to accommodate different communication styles and various types of life plans.[72,73]

Implications for In-Home Supports, and Housing Policy and Models

The evidence reviewed thus far has focused on how person-directed approaches and person-centered plans can positively influence transitions and QOL outcomes. The research consistently and significantly supports person-directed approaches. QOL values, policies, and governance models are all seen as a major influence on individuals' experience and ability to connect with the supports that help them achieve QOL outcomes.[74,29,73,50] The tension that exists between what is best understood as existing institutional practices and policies on the one hand, and person-directed planning on the other, is that the implementation of a plan is contingent on receiving supports and services within the pre-existing structures; and if these supports and services structures limit or restrict, intentionally or otherwise, the interests of the individual and their support circle, they can actually work against, instead of with each other.[75] It is therefore safe to conclude that the implementation and contribution of person-centered planning is profoundly contingent on the values, purposes, commitments, relationships and the creativity of those who practice it to garner support and resources for achieving QOL.[75] Jurisdictions that have confronted these challenges have found that planning makes its greatest contribution when values, plans, resources, and outcomes are integrated using the Quality of Life Framework, and they are based on goals that the individual helps set.[52,75]

How to Build Support at Home and in Community-based Residential Options using a QOL Framework

Evidence suggests that developing a person-centered plan, particularly within a QOL framework, helps individuals with ASD and their families move through difficult transitions.[76] But development and implementation of a plan depends deeply on parents and individuals with ASD building relationships and "sharing" their care needs and life goals with support providers who take on the values and individual needs and desires of the person they will support. This raises a major issue in in-home and community based residential living: specifically that individuals with ASD, and their families, consistently identify as a major barrier to transition a lack of access to adult service providers who are knowledgeable about ASD and evidence-based behavioural approaches that can meet the varied and particular needs of individuals with ASD.[77]

Positive
Support at
Home and in
the Community

Support Needs of Adults with ASD for Behaviours that Challenge

Large scale, individual studies have found that adults on the spectrum have many unmet needs for support and services and those that are available, inadequately accommodate or adapt to the communication, social, or behavioural needs associated with ASD.[67,78] One reason for this unmet need may be that the understanding of ASD is still emerging; another, related reason, may be that the core impacts of ASD, co-occurring frequently as it does with intellectual disability, and/or other medical and mental health conditions, means that individuals with ASD are often pushed to "traditional" service provision designed for people with intellectual disability or mental health conditions—often themselves mutually exclusive service domains. This helps explain why there has been a divide in many jurisdictions between services for persons with disabilities, and services for persons with "behavioural challenges," with supports for social communication and sensory needs often treated as a corollary or supplemental, rather than core, to the support of persons with ASD and other disabilities.

Persons with ASD are often associated with behaviours that challenge parents', caregivers', teachers', and professionals' ability to effectively support them.[24] These behaviours are characterized as "challenging behaviours" when they are intense and frequent over time and threaten the quality of life and/or the physical safety of the individual or others—therefore likely to lead to responses that are restrictive, aversive or result in exclusion.[79] "Challenging behaviour" is not a diagnosis but rather a social construct that has become an accepted term in society.[80] A more preferred term is 'behaviours that challenge' because while behaviours may be challenging to others, they may also be functional for the person with ASD, perpetuated as a form of communication and/or a response to the environmental context. Therefore, emphasizing the importance of looking at and beyond the behaviour, to the environment and those around the person, as sharing in the responsibility for both understanding and changing the "challenging behaviour".[80,81] For individuals with ASD, as with the general population, behaviours emerge early in life, evolve as one ages, and change through education, socialization, intervention, or treatment.[80]

In-home Support Needs at Transition Age and in Adulthood

At transition age and into adulthood, individuals with ASD across Canada, have a number of unmet needs[*] and the likelihood of receiving any services including behavioural and in-home support services that meet their needs decrease with age.[67] Moreover, when compared with individuals with other disabilities, youth and adults with ASD are less likely to receive support

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[*] A Canada-wide online survey was conducted to identify the priority needs of individuals with ASD across the lifespan, and predictors of receiving priority services. The researchers organized the 3,317 respondents into five age groups across the lifespan (i.e., preschool, elementary school age, adolescence, emerging adulthood, and adulthood). Priority needs included life skills training, employment training and adult programs, recreation, social skills and activity-based programs, mental health treatment, and housing.[67]

services after leaving high school[57], live independently, or live in a supported residential option, and are more likely to reside in their parents' home[82].

Parents of youth with ASD have described transitioning out of educational services as "falling off the services cliff" due to the number of service changes, the lack of both support and residential options.[67,82] Aging parents caring about and for an adult child with ASD may negatively impact the lives of all members of the household.[58] Primary carers, usually mothers, become adept at adapting their home environments, restricting employment and house schedules, reducing social time in the home, and altering relationships among family members.[83] For adults with ASD who are without school or employment, it becomes important to participate in meaningful opportunities for independence in and outside of the family home. However, finding and hiring in-home support staff (e.g., respite providers) with the necessary positive behavioural support skills can also be challenging.[83] Over time all of these experiences result in family members restricting their lifestyles and relationship patterns, as well as, adapting their environments to accommodate the family member with ASD's needs.

These conditions cause parents in Nova Scotia, and elsewhere, to worry about how long they will be able to continue to support their adult children with ASD.[84] The current residential trends of long waitlists for adult residential options emphasize the need for more accessible in-home support for young adults with ASD and their families, not only as a way to ease the needs of families, and the larger social cost associated with those: adequate in-home supports at an early age also helps pave the way for better transitions out of the family or childhood home to adult-appropriate housing.[84] Other studies conducted in Canada have substantiated this.[78,85] Therefore, it is likely that most adults with ASD, regardless of their abilities, will need some form of support to experience a quality life in any residential setting.

Evidence-based Support at Home and in Community-based Residential Options

Evidence-based Support for Adults with ASD

There are few studies published on evidence-based practices for supporting, educating, or transitioning adults with ASD at home or in community-based residential settings. In one of the leading research journals, Baker-Ericzen et al. (2018) wrote a recent editorial imploring ASD researchers to accelerate research on effective ways to support youth and adults on the spectrum to learn, grow, and cope in adulthood.[76] They argue that the recent research on neuroplasticity, the brain's ability to functionally and structurally change in adulthood[86], provides an opportunity to better understand how individuals with ASD learn, grow, and cope in adulthood. They wonder what lifelong positive impacts the ASD evidence-based approaches may make on the quality of adults' lives.[76] For this reason the following studies, focusing on support strategies for adolescents, youth, and young adults, will be generalized to inform evidence-based support strategies for adults with ASD of all ages.

Parents use of Evidence-based Support

While many parents of children with ASD have no prior professional training in the area, many learn evidence-based, behavioural strategies to support their children. Studies have identified parenting strategies used at home and in the community as including: accommodating their child; managing non-compliance with everyday tasks and activities; responding to behavioural challenges; managing distress; supervising; monitoring; modifying the environment; providing structure, routine, and familiarity; maintaining safety; and analyzing behaviour and planning. Parents had many ways of preventing behaviour, deescalating behaviour, and reacting to meltdowns. Many of the strategies employed, targeted the vulnerabilities that come with ASD, and which persons with ASD experience in their day-to-day lives: such as sensory sensitivities, aversion to change, transitions, and communication.[87] Overall, results suggest that although parents are competent and know how to support their children well, providing care is demanding and can quickly exceed their capacity and resources alone. This is particularly relevant as children with ASD age into adulthood, and parents discover the lack of service providers with training in evidence-based practices for supporting adults with ASD—making it difficult to transition them from a family or childhood home to an adult arrangement.[87]

The research published to date supports the following evidence-based practices for youth and young adults with ASD (15-22 years-old)[34] (see Appendix F for definitions):

Evidence-based Practices
Antecedent-based intervention (ABI)
Cognitive behavioral intervention (CBI)
Functional behavior assessment (FBA)
Functional communication training (FCT)
Self-management (SM)
Social narratives (SN)
Technology-aided instruction and intervention (TAII)
Prompting (PP)
Reinforcement (R +)
Differential reinforcement of alternative, incompatible, or other behavior (DRA/I/O)
Response interruption/redirection (RIR)
Extinction (EXT)

Experts emphasize the need to move these evidence-based strategies into mainstream practices, programs, and models—to prevent unnecessary out-of-home placements and hospitalizations as a form of stabilization or intervention. However, given the diverse constellation of the spectrum, practice models tend to be technically eclectic, though all based on behavioural principles to achieve the desired outcome and accommodate the unique profile of the individual. Most of the research in this review was conducted in schools, clinics, community, and home environments. Based on this review there were no research studies conducted with direct support staff using evidence-based strategies in families' homes or in supervised or assisted residential settings for youth or adults with ASD.[34]

Evidence for In-home Support

In-home support can be beneficial for all family members, especially as youth with ASD are transitioning from high school and pursuing next steps toward living independently. In-home support may be provided by unpaid or paid caregivers. Unpaid, informal supports are typically family members, friends, and other parents. However, as children with ASD age, parents are less likely to access *unpaid* support because those who provide it, for example, grandparents and siblings may be no longer available or able to provide support. As parents age and their children with ASD become adults, it is therefore natural and necessary that families engage both unpaid and, increasingly, paid in-home support. Those who provide formal supports work within formal systems, for example, an organization, agency, or institution which may include health and education professionals, care co-ordinators, and disability support providers.[88]

Research on support has mostly focused on parents of young children and its benefits for parental health and quality of life. However, a recent study examined the relationship between unpaid informal and formal supports and their effect on caregiver burden and parental quality of life in parents of adults with ASD. They found that unpaid informal support was helpful in decreasing caregiver burden and enhancing quality of life. The most commonly used formal supports were psychiatric services, financial support, and counselling. In this study, formal supports had no effect on either caregiver burden or parental quality of life. The authors suggest that in contrast to unpaid supports, formal supports were either lacking (i.e., quantity and quality) or were directed toward the individual with ASD.[89] Researchers suggest that these findings support the need for more and higher quality in-home (e.g., respite care) and consultation services that have a better understanding of ASD, the impact of ASD on daily routines including, but not limited to, behavioural challenges, and the resulting complexity in providing care and support.[90]

Evidence-based In-Home Support: Respite Care

One avenue of formal support that is being enhanced to better meet the needs of both parents and their adult children with ASD is in-home support for respite care. Historically, respite care has been defined as relief from care, providing a break for the caregiver.[91] However, over the last decade, respite care has been recognized as providing positive opportunities for children and adults with a disability to gain independence and improve their quality of life, as well as providing a break for the whole family.[91,92] As such, respite has benefits for families, individuals with ASD, society as a whole and, by extension, governments.

Identified factors positively associated with high-quality respite services for individuals with ASD include a consistent use of evidence-based approaches across settings, a structured physical environment, use of ASD appropriate approaches, staff with skills and understanding of ASD, individualization of activities and services, and available as well as accessible community programs.[91] Respite providers must act as one part of a continuum of support by working together with families, community service providers, teachers, social workers, therapists, professionals and other parties.[91] Typically funding for in-home respite either goes directly to the family or to a respite service provider. Out-of-home respite is typically provided by a service provider, involves overnight stays, and families are eligible for a specific number of hours or days per year for this service.

Research on in-home supports through respite shows that positive benefits are experienced by families and individuals and broadly beneficial for family health. Respite care prevents marital breakdown and improves marital quality for both fathers and mothers.[93] Evidence suggests effective respite reduces family stress and helps families stay together, allows time for activities that are difficult for an individual to do at home, and allows parents to give more attention and time to siblings, to invite friends into their home, and enjoy a break from their caring role.[91,94]

The benefits of respite for individuals include increased life skills and independence[94], improved social skills and relationships[94], and reductions in challenging behaviour[95]. Overall, respite improved social and educational opportunities and provided steps towards greater independence and adulthood.[96] Most importantly, it supported individuals with ASD to live with their parents. In particular, respite supported older parents to continue to provide care rather than seeking an out-of-home residential placement.[97]

A comprehensive review of the research on respite found that while in-home respite is characterized as providing support in the family home, out-of-home respite is characterized as parents moving toward relinquishing the care of their son or daughter.[98,99] This is mainly because out-of-home respite care is sought when there are barriers to accessing sufficient quality and/or quantity of in-home respite care. Those barriers are generally associated with the highest levels of dependence and behaviours that challenge.[95] Studies show individuals with ASD and behaviours that challenge are least likely to access respite services in general.[91,95,96] The reasons for exclusion include a lack of "autism-friendly" services, respite providers lacking the skills and understanding for supporting individuals with ASD, and individuals experiencing a poor fit with the environment.[91,95,96]

From a program and policy perspective, whether individuals receive respite at home or out-of-home, there is a dire need to prioritize and bolster the quality and quantity of respite to support family caregivers and prevent premature out-of-home placements.

Evidence-based Support in Community-based Residential Options

The current generation of youth and young adults with ASD who will be, or are already, looking for residential support have grown up with care providers and educators who have used evidence-based behavioural practices to support daily life and create welcoming ASD-friendly environments in their homes (e.g., O'Nions et al., 2018), pre-schools, and schools (e.g., Wong et al., 2015). Practice and research experts emphatically stress the importance of using these evidence-based and positive behavioural practices with individuals with ASD because it is imperative for promoting health and wellbeing.[96,,97,98] Therefore, these skills are critically important for residential service providers who are invested in promoting quality of life and preventing crisis, physical and medical restraints, and hospitalizations.

Research on the implementation and efficacy of evidence-based practices in supervised residential settings for adults with ASD (e.g., funded homes with 3 or more people) is sparse. The majority of residential sector studies have focused on direct support for adults with intellectual and developmental disabilities (for a critical review of these studies see Caler, 2018)[103]. Research with adults with intellectual and developmental disabilities has shown that support providers' positive attitudes, values, and use of evidence-based practices, translate into more positive interactions, as well as, job satisfaction.[103]

Research has found that support providers' attitudes and values were integral to the successful day-to-day support of people with intellectual disability and challenging behaviour.[104] Support providers' attitudes influence their own behaviour and the behaviour of the person they are supporting, creating a reciprocating effect. So while challenging behaviour is often associated with social, biological and environmental factors, it can also be associated with negative interactions between the carer and care-recipient.[104–107] The likelihood of negative interactions may increase if support providers mistakenly assume an individual with ASD's challenging behaviour is intentional and/or unnecessary. Support providers attributions to the causes of challenging behaviour and their uptake of evidence-based practices mainly depend on the training they have received and their personal attitudes, levels of stress, as well as on the values of the service organization.[106,108]

Implementation of Evidence-based Supports Including Positive Behavioural Supports (PBS)

A review of studies examined the implementation of non-restrictive, evidence-based practices such as positive support plans, and the efficacy of positive behavioural support (PBS) by residential staff, with the most challenging behaviour of people with ASD and other developmental disorders.[100] The findings showed that PBS strategies were easily employed by staff, effective with both severe and high-rate behaviour problems, was cost-effective, and worked in institutional settings, as well as in the community. **The authors concluded that the major implication of this review was that positive behavioural support plans, using the least restrictive method of support, were effective for people with the most challenging**

behaviour. Given the effectiveness of these non-restrictive practices, experts argue that **practitioners should be ethically obligated to use them, when faced with the need to develop a plan of support for individuals with challenging behaviour**.[100]

To improve the quality of behaviour support plan implementation, researchers conducted staff training designed to decrease the use of restrictive behavioural and medical interventions and increase the safety and quality of outcomes for adults with intellectual disability who engage in behaviours that challenge.[109] The training program was based on the principles of positive behavioural support best practice. Post-training the quality of the behaviour support plan and client outcomes were evaluated and compared to a matched control group. Overall, findings showed an improvement in the mental health and behaviour, the quality of the implementation of behaviour support plans, and staff used less restrictive interventions.[109]

Implications for In-Home Supports, and Housing Policy and Models

Taken together, staff attitudes, values, and training along with quality of behaviour support and person-centered plans for individuals contributed to positive outcomes for people receiving, as well as those giving support. Overall, this literature shows a compassionate workforce grappling with residents' challenging behaviour and balancing residents' autonomy and rights with safety[110], struggling with personal attitudes and workplace values[104,111], and aligning daily practice decision-making with individuals' person-centered QOL plans and agency policies[112]. These findings coincide with the evidence of a general lack of professional practice guidelines for Direct Support Professionals (DSPs). Jurisdictions in Canada (see Appendix G) and elsewhere have begun the process of developing professional practice standards (USA, UK, and Australia).

According to researchers and policymakers, the future success and effectiveness of services for people with ASD and other developmental disabilities depends on a well-trained workforce of direct support professionals (DSPs), modifying and creating supportive environments within residential settings, and guided by a responsive wraparound organizational structure and governance model. [52,113,114]

PART 3: ASD at Home, in Residential Options, and in the Community

ASD at Home,
in Residential
Options, and in
the Community

Self-advocates, family members and ASD service providers report that determining "fit" is a process and practice of assessing the built environment through the eyes of the person with ASD. For people with ASD, or any disability, living with their families or being "placed" in housing and becoming a "client" does not always translate into a sense of being "home". Home is more than a place or a space. Home is the feeling and a state of self-determined living, with privacy and freedom to withdraw from the outside world, and a haven for relaxing and acceptance.[115]

Why Adaption is Important for ASD

Where someone lives can have a profound impact on their quality of life, health, and wellbeing.[116] For individuals with ASD, the occupancy type, buildings' design, and adaptions can have an impact on sensory experiences and behaviour, contributing to their overall health and wellbeing. Using a holistic approach, the building design and level of personal support must be tailored and individualized to meet the complex needs of ASD.[116] The abilities and sensitivities of individuals on the autistic spectrum vary greatly, so reactions to different environments can differ. In an ideal environment, home is a space that facilitates security, safety, control, domestic comforts, and identity.[83] However, if the home 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.[83]

For those with ASD, a difficult home environment can contribute to or cause isolation, loneliness, and be infused with negative meanings.[117] Home adaptions are necessary for creating a home environment that someone with ASD can trust. Some individuals with ASD rely on orderly environments in which everything must remain precisely the same to avoid disorientation or disruption of routines. **For people with ASD, no person, place, or thing is predictable in its perceptual impact.[83] While there are some overlaps with conditions such as mental health disorders, intellectual and developmental disabilities, the particular social and sensory idiosyncrasies of ASD necessitate the importance of producing diagnosis-specific housing plans for individuals with ASD.[83]** Even though there are aspects of ASD that can be predictable, ASD as a whole is not a predictable "one size fits all" condition and the needed adaptions should be individualized.[117]

Types of Supportive Residential Living Options

A variety of residential options exist for individuals with ASD. Broadly, these categories include: supported living, supervised living, group homes, and transitional living.[116] Within each category there is a certain degree of variation and overlap in the features or characteristics that define it.

Supported Living

Supported living is when an individual lives in a place of his or her choosing, either alone or with a roommate, with some support from family and friends or from an off-site caregiver.[116] Supported living includes a person-directed approach and focuses on providing choice and building social connections. Although there are several types of supported living arrangements, the typical version is one where care providers come into the individual's home.[118] 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 by implementing "smart home" assistive technology in the home and augmenting the technology with behavioural and medical support from a family member and/or a service provider.[117] This tenure 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. For example, home sharing with a family[119] or shared living in a single-family home where there is substantially separate space aside from a shared kitchen or living space.[117]

In this model, housing can be separated both financially and organizationally from support staffing.[120] For this type of 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.[121] Extensive research and evaluation demonstrates that supported living is effective for most individuals, regardless of ability, and is a less costly model than group homes.[112,120–124] Those with the best QOL outcomes were autistic, younger, and had better health, had previously lived with their family, received fewer hours of support and more family support, had a person-directed plan, employment in a non-segregated setting, and were involved in their community.[120,125]

Community-based Small Option Homes

Community-based small option living is an accommodation where the majority of support comes from a source other than immediate family. This supported housing type is often determined by the service type.[116] In some cases one to four individuals with or without ASD may live in each unit, 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 may be 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 adults with ASD, is another emerging practice in community-based small options – although this model is only available in some areas.[117] An example of an innovative model of community-based intergenerational housing comes from Phoenix Arizona's 29 Palms. Included at 29 Palms are 15 units for seniors and six units for adults with ASD. 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 adults with ASD, this model can also serve as transitional living (see below), as life skill training and independent living are goals of the project.[126]

Supervised Group Homes

A group home is a housing option where a number of individuals (e.g., 4–6+ people) all live in a licensed home. [116,117] Support is provided by hourly workers who work for an agency/service provider or the province. The home may be privately owned, an agency, or a third-party landlord, or by the province. This residential options are typically regular neighbourhood homes with a small footprint, resulting in lower housing costs.[117] However, it also has the potential to be inflexible and less person centric because of the number of people in the home and the combination of housing with 24-hour support. For example, more people living in a home may limit individual choice and be less responsive when support needs change or possibly provide more support than necessary.[112] Outcomes are best in ordinary homelike settings that are dispersed rather than congregated within any one community.[112] Outcomes are better where there are skilled staff empowering people to do things for themselves and when people are not grouped together by level of disability or by behaviours that challenge services.[112]

Transitional living

Transitional living is when housing is part of intensive life skills training. Transitional living is meant as a stopping point for residents, who use the living arrangement to learn the skills that they need to live independently.[117] 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. For a different skill set, 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.[117]

Co-housing: Multi-Unit, Inclusive Universal Design Communities

Large, inclusive, multi-unit housing that includes autism friendly universally designed features incorporated into the building's construction are good examples of successful models for residents with ASD.[117] In some cases, individual apartments, condos or homes may make up part of a community where residents with ASD and without ASD co-exist as neighbours in their own individual spaces. A facilitator, a neighbour or both, are paid to facilitate connections and provide support.[117] Existing zoning bylaws consider either the type of space (e.g., residential, commercial) or the form type (e.g., building height or width), rather than considering more specifically who that space is meant for.[127] In the future, zoning that includes a requirement where a percentage of units have autism friendly design features already incorporated will pave the way for more inclusive housing and communities. An innovative example is “Sweetwater Spectrum”, a non-profit organization in Sonoma, California dedicated to exploring, building, and evaluating a community conscious housing model for adults with autism. 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.[128]

Adapting for ASD Friendly Spaces

Although individuals with ASD have interests as varied as any neurotypical community, there are some unique aspects of design and construction that are necessary because they contribute to the wellbeing of an individual with ASD.[116] Safety, familiarity and clarity, minimizing sensory overload, privacy, choice and independence, durability and affordability are all common themes that can contribute to an autism friendly design.[126] 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.[129] In certain cases, if the proper environmental accommodations are in place, then living independently may become a possibility.[126]

Sensory Profiles

Some adults with autism seek out sensory experiences (hyposensitive), while others try to avoid them (hypersensitive).[126] It is therefore essential to provide environments in which the visual, acoustic, olfactory and tactile qualities can be modified to suit a person’s preferences and to eliminate their sensory barriers or triggers. Many people with autism experience unique reactions to sensory inputs, which affect the way they perceive the world around them.[116] Living in a world that does not take into account their sensory responses can give rise to high levels of anxiety, which in turn may trigger challenging behaviours in the form of aggression, self-injury, repetitive actions or disruptive and destructive behaviour.[117] It is recognized that these behaviours may be largely involuntary and may be caused by communication challenges.[117] It is beneficial for adults with similar sensory needs and abilities to live in the same building, or in cases where an adult has extreme sensory sensitivities, to provide a single person household.[117] The differences in sensory needs between individuals with ASD varies greatly, that is why homes are more likely to be successful when the compatibility of residents has been assessed and people are living with others with complimentary needs, routines, and at similar life-stages.[116]

In order to minimize sensory overload, an environment should be designed to be quiet, visually calm, well ventilated and with appropriate lighting features.[116] Fluorescent lights should be avoided as they produce a flicker that can be a trigger for some individuals.[126] Indirect lighting on reflective surfaces minimizes glare, which some may find distracting.[117] Familiarity with the environment helps to create a sense of stability and clarity. To incorporate familiarity into building design, the use of familiar materials and logical spatial layouts are necessary.[117] While activity spaces should be accessible by all residents of the home, noise and unplanned interruptions may be minimized by locating the sensory space (see below) away from activity rooms, main circulation spaces, communal rooms and utility areas such as a laundry room.[117] Soft or porous floor materials may also reduce noise transmission.[130] Another way to ensure noise reduction performance of a building is to separate floors and walls using suspended ceilings, sound absorption materials, cavities, sound resistance plasterboard or acoustics tiles – in certain cases, acoustic glass may be required for road-facing windows.[117] Central ventilation, along with acoustic insulation, will minimize extractor fan noise created by the necessary ventilation systems in new builds or retrofits.[116]

Limitations associated with various sensory and social preferences can be challenging, especially when they differ between the individual with ASD and other members of the household.[83] To accommodate for a variety of personal preferences, the design of any home should provide residents with a variety of sensory and social opportunities, including within a singular space.[130] For this reason, the space plan of a building is incredibly important. Sensory focused activities do not have to take up the space of an entire room, yet certain activities, such as pacing, dancing and jumping, require a larger space than most other activities.[117] Hanging fabric can be used to redefine larger spaces, they even work to soften hard features like room corners. While sensory overload should be avoided, fabric can sometimes be useful for the projection of colors or other imagery that aligns with the individual's sensory needs and wants.[117] The placement of furniture can be used to define smaller spaces or segments within a room as well, but it is equally important to arrange objects so that movement is not obstructed.[116] Furniture and fabric are both easy to move or remove, making the space endlessly reconfigurable to meet the changing needs of residents, or simply for different types of activities that may require more or less space.[117] Different flooring materials, textures and colors may also be utilized to define spaces within a larger room.[116]

Many sensory activities may involve the use of different tools that will need to be stored after use. Storage units and shelving may be covered or fitted with doors to maintain a low-arousal environment.[117] When possible, storage space can also be built into architectural features, such as under a staircase.[116] Visually organized space is both predictable and calming and can also provide, where necessary, additional security and structure for the resident by providing a space with controlled access to certain items or resources.

For individuals with ASD, the sensory experience of home is contingent on social and building material factors (see the chart below constructed from several sources[116,126,131–134]).

Sensory System	Indicators of Hyper-Reactive Responses	Indicators of Hypo-Reactive Responses	Adaptions to Prevent Reactive Responses
Visual System	Disturbed by bright light Avoid sunlight Follows any movement in the room with eyes Blocks field of vision with eyes Covers parts of visual field – puts hands over part of the page in a book Responds physically to appearance of certain objects	Unaware of the presence of other people Unable to locate desired objects, people Loses sight of people or objects when they move Cannot distinguish figure-ground relationships	Ability to control light: - Dimmer switches - Window Treatments Avoid fluorescent light sources Windows on one wall reduces distractions Glazed or frosted windows allow light to come in without producing glare Matte paint and other surfaces also reduce glare Large amounts of colour are overstimulating Large windows and doors allow areas to be 'previewed' along with providing views of nature Wall decals add visual interest and can be easily changed Food pantries and rotating shelves give good visual access
Auditory System	Easily distracted by background sounds Overreacts to sounds Unpredictable reactions to sound Holds hands over ears to block noise Screams or cries at sounds in the environment Responds physically as if sound is a threat	Does not respond to name being spoken Seems oblivious to sounds of surrounding activities Creates constant sounds as if to stimulate self Unsafe because does not react to sounds indicating potential danger Does not respond to any kind of sound	Avoid sound reflecting surfaces and floors that contribute to reverberation Provide a stereo to listen to music and other sounds Install sound absorbing panels Tennis balls on chair legs reduces noise when they are moved

			Utilize headphones to block out additional noise Soft materials also contribute to noise reduction Water features provide soothing sounds
Tactile System	Touch defense – does not like to be touched Avoids tasks with strong tactile element (clay, water play, paint, food preparation) Complains about discomfort of clothing Refuses to wear certain items – tugs at clothes Responds negatively to textures in food, toys, furniture	Does not seem to grasp concept of personal space Does not seem to notice touch of others Frequently puts things into mouth Does not adjust clothing that would seem to be an irritant High pain threshold, unaware of danger because of low response to pain	Weighted blankets to apply deep pressure Many individuals enjoy smooth or shiny surfaces, such as counter tops and shiny floors Areas where hands on activities (such as clay or paint) can happen Many individuals enjoy soft textures (such as stuffed toys and blankets), while others do not Heated floors and temperature controls to regulate the environment
Vestibular System	Overreacts to movement activities Has difficulties navigating on different surfaces (carpets, grass, etc.) Walks close to wall, clings to supports such as banisters Seems to be fearful when movement is expected, muscles seem tense Rigid about positioning of body, keeps head in same rigid angle	Seems to need constant movement Rocks, travels in circles Seems to tire easily when engaged in movement activities Generally slow to move, lethargic in movement Takes long time to respond to directions to move	Interiors should be made of defined forms and shapes Contrasting floor materials aids in wayfinding Spacious walkways or walking loops Durable materials that can withstand spatial needs Minimal number of doorways to avoid confusion Provide supports in the built environment that accommodate

	Seems to become physically disorientated easily		vestibular and spatial needs Grouped swings or benches provide opportunities to socialize and enjoy vestibular input Barrier-free entries to accommodate for mobility challenges

Health and Well-being

To address any ongoing health vulnerabilities, the physical design of a structure should promote healthy living through the use of non-toxic materials, the availability of natural light, good ventilation and the incorporation of universal design strategies (for more on universal design, see Brand, et al).[116] It is as important to address core health issues as it is to enhance the quality of life of an individual. For people with ASD, many co-occurring health conditions are likely, therefore health and safety should be paramount when providing housing to individuals with ASD, but the design contours and structure must be addressed on a case by case basis.[117]

Every aspect of the home should work to enhance an individual's dignity and well-being.[116] Everything from selecting a neighborhood that accepts diversity and supports its residents, to designing a home that allows residents to personalize their spaces and define their living arrangement.[117] The physical environment should be designed so that options are available and flexible so that it can be adapted to changes in residents' needs over time.[116]

For health and well-being, the outdoor environment is as important as the indoor environment.[135,136] The research on the health benefits of green spaces and outdoor environments has shown many benefits for the well-being of children, youth, and adults with ASD.[135,136] Outdoor environments have many positive effects on productivity, purpose, and well-being.[135,136] Safe access to green spaces, transportation, community services, entertainment and shopping, coupled with a supportive neighbourhood community will create the best possible quality of life for individuals with ASD.[117]

Safety and Durability

Living in a safe and durable home is a high priority for individuals with ASD and their families because of the abnormally high risk for accidents and injury to occur at home and in the community.[83] While it is important to ensure that any home is built or remodeled with safety in mind, it is equally important to do so without infringing on individual independence, choice and control.[117] All aspects of a safe environment should be determined on an individual basis[116] and anticipate preferred activities to maintain rather than restrict individuality and wellbeing. Inside and outside the home, alert systems, security systems, web interfaces and central call systems all contribute to creating a more secure environment.[117]

Safety and durability depend on a number of general preventative factors. For example, investing in high-quality materials, fixtures and appliances at the outset will result in lower maintenance and replacement costs, and optimize resident safety.[117,130] Safety and durability is especially important when considering the materials being used in spaces where highly stimulating activities will be taking place. In some rooms, floor covers may benefit from more durable and waterproof materials – some individuals like to interact with the environment in unusual ways, such as banging on window panes or engaging in water play, which could cause property damage.[117] Due to sensory processing differences among persons with ASD, door handles and faucets can easily be broken by using too much force.[117] For some individuals reinforced walls and windows are necessary.[117] To accommodate safe jumping and bouncing, considerations for wider spaces and larger areas are also necessary.[129] Durable materials will only work in so many instances, therefore it is necessary to ensure that maintenance is conducted regularly and repair tools are available to address common problems. Investments in high quality commercial appliances, installing a mop sink and strategically placing floor drains can all enhance safety and defray costs, in the long term.[116] Safety and durability can also be improved by adhering to physical accessibility building standards (see the Nova Scotia Accessibility Act here).[137]

The kitchen and bathroom are priority areas for safety and durability. While there are common issues and fixes, for example ground-fault electrical receptacles, water flow and temperature sensors to avoid floods and burns, sturdy fixtures that can sustain hard use, and the storage and use of cleaning supplies, there are unique issues to consider as well, which will be highlighted below (please note the following is not an exhaustive list of safety precautions).

The kitchen is a high-risk area in any home. Potential safety precautions include concealing the sink and appliances, and locked cupboards for cleaning supplies.[129] The stove is a major safety consideration and precautions must be taken with the heating elements and oven door. Cover the electrical plugs. Provide a safe location and a cooling area for small appliances, such as coffee makers and kettles. Any devices or appliances that emit light or turn lights on and off are another safety consideration. In some cases, cupboards which contain food that could be choking hazards and sharp objects should also be locked when not in use. Labeling areas of the kitchen with visuals of words and/or symbols to explain their function and set safe boundaries around their use can also provide cues for safely using appliances with minimal support.

There are many common problems that can take place in the bathroom. For this reason, including aspects of “The Essential Bathroom” may help alleviate the challenges that arise. A bathroom must first be large enough to not trigger defensiveness or discourage participation in toileting or bathing activities.[138] While the size of the room is important to consider, the physical accessibility of the space, as well as the style and placement of the toilet and toilet roll are equally important. Ensuring that the toilet is positioned in a way that maximizes the space available for its use can help encourage toileting independence. There are a variety of ways in which injuries can take place in the bathroom. In order to maximize safety, it is essential to install non-skid flooring, weight-bearing bars with solid backing, Ground Fault Interrupter outlets, tempered glass and mirrors, and tempering/balancing values. Because of the amount of water being used in bathrooms, installing a floor drain would assist with mopping up any water that gets splashed or spilled on the floor. Institutional or commercial grade fixtures are often much more durable and effective than the fixtures found in most homes. While grab-bars can help improve safety and stability, they are only as effective as the structure on which they are mounted. Installing a continuous sheet of plywood or extra wood backing can help to improve the stability and durability of the surface on which the support is to be mounted. While bathrooms are not always located on an exterior wall, including natural light in any way possible should still be paramount. Other than operable windows, exhaust fans and good ventilation are necessary in any bathroom environment. Secondary heat sources, such as radiant heating in the floor or heat lamps, can create a more welcoming environment for people who are temperature sensitive. Eliminating floor registers and other floor openings that could collect dust or water helps to contribute to maintaining the cleanliness of the bathroom environment.[138] Finally, all of these adaptations are meant to provide dignity, maximum support and independence.

Adaptations to common areas and bedrooms mainly focused on enhancing safety by reducing sensory demands and ensuring spaces are organized and clutter free, through “lighting control, soundproofing, and increasing storage spaces to reduce cluttering”[129(p157)]. “Safety strategies include using locks on doors and windows, fixing gates on the stairs, and using alarms on doors”[129(p150)] as well as securing television and computer screens behind Plexiglass and minimizing furnishing with sharp edges.[129] Some families have converted walk-in closets into sensory rooms with low lighting, pillows, favourite fabrics, and calming sensory toys.[129] Ensure that bedrooms and quiet spaces are not located too near loud or vibrating appliances such as washers and dryers unless the individual prefers these noises (i.e., some may find these calming while others may not). Accidents can occur when individuals with ASD are trying to escape overwhelming sensory or social situations, therefore it is important to provide safe spaces for self-regulation and comfort in their homes. These household modifications hold many benefits for individuals with ASD, their roommates, and their carers.[129]

Safety and security extend beyond the usual home environment as well, to include the backyard, and surrounding neighbourhood and neighbours. For those who are at-risk for elopement, securing an outdoor space with fencing gives opportunities for outdoor play, recreation, and independence.[135] While a safe neighborhood is imperative for individuals with ASD, a safe neighbourhood is made up of safe surrounding neighbours.[117] Some people with ASD engage in behaviours or stimulatory activities that may be disruptive to the surrounding neighbours if there is a lack of understanding; for example, sleep disorders are common among individuals with ASD, therefore behaviours or loud stimulatory activities are not limited to the daytime. Likewise, loud neighbours in detached or attached home environments may contribute to sensory overload of individuals with ASD, or contribute to sleep difficulties.[117] It is important to note that a lack of safety and durability can place limitations on the autonomy and freedom to use a space independently which may negatively affect the experience of 'home'.[83] Chief among these limitations is affordability, which in the short and long term, can be achieved by incorporating green building practices that can lower costs over the lifetime of the home.[116]

Person-directed Planning for Housing and Support

Regardless of the housing design or location, individuals with ASD should have the opportunity to collaborate in the look and feel of their home. Gaudion et al. (2015)[139] have developed a resource to support designers and service providers to work with people with ASD, with limited or no speech and additional learning disabilities, to include them in the design process. "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." [139]

There are individuals on the spectrum for which conventional housing can not work, because of behaviours that challenge the infrastructure or support providers and the housing stock available to them. Those who design housing for individuals with ASD insist that "you cannot fix a problem behavior in a broken environment" and proper "modifications to the home can often reduce the cost of supports".[117] Braddock and Rowell 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 and 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 imperative in selecting, adapting, and developing housing for the ASD community.[119]

Example of an ASD Community Consultation: MA Autism Housing Think Tank

Massachusetts Autism Housing conducted an exemplary community consultation process with a group of individuals with ASD, their family members, service providers, officials from state human services, housing agencies, and builders came together for a one-day ASD-housing "think tank". The "think tank" members brainstormed appropriate housing options and identified models that might be built with public or private funds, or through public and private partnerships. Barriers and solutions identified by this “think tank” are likely to be applicable to other ASD communities in Nova Scotia.[117]

The impetus for the ASD-housing “think tank” was based on identified barriers for individuals with ASD who were interested in residential options. Those barriers were:

- poor understanding by individuals and families of existing housing options;
- affordability;
- long waits for housing;
- a poor fit between the requirements of some programs and the desires of the individuals who are in need of support;
- zoning provisions that bar creation of accessory apartments;
- lack of funding for assistive technology that could facilitate independent living;
- and wages for live-in caregivers.

While these challenges were identified by the MA housing group, it is important to note that even if all of these challenges were to be alleviated, existing housing stock may fail to meet the sensory and support needs of many people with ASD. ASD friendly design is needed to help people maintain tenancy and find comfort in their homes.

The “think tank” facilitation process followed a “working” format with concurrent data collection (see the footnote below for links to information they gathered and disseminated in advance of the think tank day)[*]. The participants were divided into 6 groups and each group was given hypothetical profiles of residents with ASD. The groups identified appropriate housing models, environmental design features, and assistive technology options for each of the resident profiles. Finally, they discussed possible funding streams and the barriers to implementing the identified housing models. After a lunch break, participants rotated to a different group so that each profile could benefit from two assessments.

Of the 12 housing models being considered, the following five housing options were selected most frequently:

1. Individual apartments or condos in the community, located close enough to one another to permit socialization. For these apartments, a facilitator and a neighbour would both be paid to provide support and create connections in the community.

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[*] 1. Developed a dedicated website to provide background information on the housing situation for people with ASD (e.g., defining-the-need/ and autism-friendly-design/).
2. Used Facebook to develop ASD housing principles and explore possible models, (best-practices/).
3. Hosted webinars on the use of assistive technology to support independent living (technology/).

2. Shared living in a single-family home that would be owned or leased by the family, an individual or a third party. It could involve substantially separate space with a shared kitchen.
3. Co-housing is an intentional community of homes, each having their own amenities and also clustered around shared space which may include a large kitchen and laundry, a garden, or recreational spaces.
4. Small footprint units that would result in lower housing costs. The units would have trained management and/or support providers.
5. Transitional housing with the purpose of educating residents in the skills that they would need to someday live independently in the future.

Based on these housing models, the group identified further ASD friendly housing design features. As with housing models, certain features were more or less important depending on the specific resident profile. It was found that housing and support barriers needed to be addressed on an individual basis due to the ASD spectrum. Staff training, caregiver shortages, quality housing shortages, and the need to pay for assistive technology and/or for life coaching were also cited as being areas of concern. Apps for cueing, daily life, decision-making and coaching were also identified as being useful yet underfunded. Alert systems, including a central call station with a web interface and support team. Zoning and ASD accessible building standards, and builders knowledgeable about ASD, were also identified as priorities for creating housing options.

The final portion of the think tank was a discussion of possible areas where changes should be made and about the difficulties individuals and their families experienced when looking for housing and support. Overall, the group identified the need for better communication across agencies – individuals, families, teachers, support staff, and service providers. The one-day think tank process led to a state-wide survey of available and acceptable housing options appropriate for individuals with ASD.[140]

The following is the scope of work conducted in MA:

A survey was conducted to capture the current availability of supportive housing units to people with ASD, including all housing units that can be used with individuals with ID and ASD. Units that can be used by individuals with ASD and no ID, shared living options, and units that included up to 24/7 support services, including a determination as to whether these units are fully utilized;

Family focus groups and a consumer focus groups were conducted in order to gain additional information regarding the housing needs and preferences of people with ASD; and

An analysis of the types of housing models and units needed to meet the supportive housing needs of individuals with ASD.

A survey was conducted with the ASD Service Coordinators and Providers.

Implications for In-Home Supports, and Housing Policy and Models

A critical aspect of planning for adult life with individuals and their families is considering the spectrum of abilities and the supports that will be needed to live well in the community. A "one size fits all" approach will not work for the ASD community. Planning will require a menu of residential options that can be individualized, as is the autism spectrum itself, to ensure ASD friendly environments in the family home or with support, living in the community. Transitioning to adulthood and person-centred planning for independent living, skill building, social inclusion and connections to the community as well as employment services. In an ideal scenario, housing options ought to be developed through a person-centered approach with a view to achieving a more meaningful, holistic quality life. This means addressing the full range of sensory, clinical, behavioural and physical needs, the role of technology, and the need to resolve jurisdictional issues across services, funding sources, and government departments.

PART 4: Positive Behavioural Support Wraparound Services

One of the biggest challenges that confront individuals, families, support providers, and policy makers, is the question of what tools, training and tactics are necessary to build the support capacity of the whole system. For the most part, once individuals leave their family home, residential service providers and direct support professionals are the main point of day-to-day operational support for people with ASD and/or intellectual and developmental disorders. In Nova Scotia and elsewhere[114,141] there is widely accepted recognition that any framework for supports must provide "wraparound" services, and that such an approach will improve outcomes and provide much needed guidance for service providers and staff as they strive to continue to provide the best possible care for individuals, particularly those with complex care needs.

Positive Behavioural Support Wraparound Services

Positive Behavioural Support (PBS) is a recognized "wraparound" approach.[142,143] It wraps around the individual with ASD by bringing together family and carers and committed professionals to develop and implement person-centered and directed plans. It is an approach that integrates all of the evidence-based strategies reviewed in this report within a practice-oriented evaluative framework to guide individualized planning and support for people with ASD and other behavioural or developmental disorders. Positive behaviour support extends the theory of Behaviour Analysis and also prioritizes the quality of life, with a positive appreciation for person-directed values[144] and neurodiversity[32]. Accordingly, the approach is guided by person- and family-directed plans using a human-rights and behavioural approach to assist people to achieve their goals. The fundamental goal is to create a common understanding so that people with ASD can experience a sense of well-being with opportunities for developing skills that contribute to a good quality of life.[144]

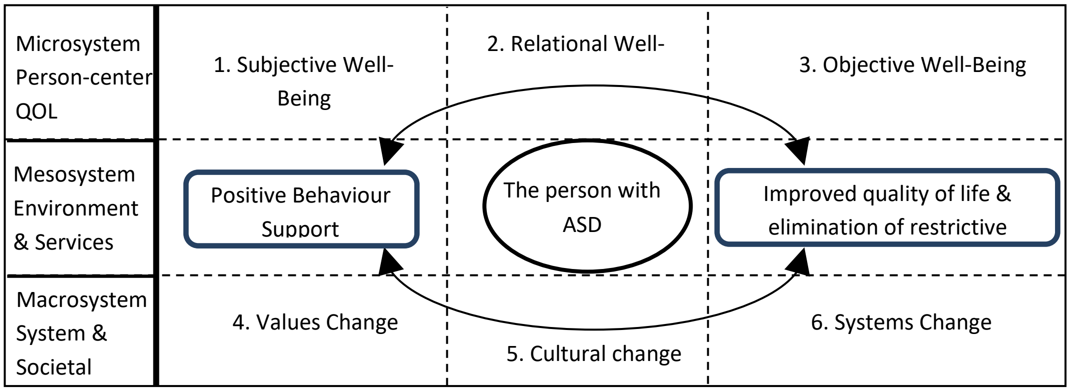
Positive behavioural support was specifically developed as an approach to prevent and treat behaviours that individuals often learn as a form of communication.[144] Reviews of evidence suggest that parents, carers, and service providers can be trained to deliver positive behavioural support in any setting (e.g., home, school, work, and community programs).[145] The approach objectively assesses a situation and the challenging behaviour yet values the individuals' character and interests.[144] As such, it looks beyond the individual to the social and physical environment, interactions with support providers, and the service-/system- level influences that are all associated with reducing and treating, as well as escalating, challenging behaviour.[102,146] Therefore, positive behavioural support provides core values and principles as well as framework for overall service delivery.[147]

Positive behavioural support has been effectively used across the lifespan and applied in natural settings.[145] For individuals with ASD, challenging behaviours frequently originate in childhood or adolescence, but these behaviours can persist or new challenging behaviours emerge at any point in an individual's life.[21,148] Additionally, where individuals live and the people they live with are all a part of the process for planning and teaching new ways of communicating and developing new skills for living a quality life. The process typically involves positive behavioural support specialists, in consultation with the individual with ASD and their family, going into the home, school, or workplace, and developing interventions by assessing what functions the problem behaviour appears to be serving, given biological, psycho-social and environmental factors. Consequently, a comprehensive model for supporting individuals with ASD must be delivered across the child-/adulthood divide of service provision and involve close collaboration between families, caregivers, agencies, and possible government departments.

Positive Behavioural Support Implementation

Drs. van den Akker, Edwards and Soo conducted an extensive review of primary studies and a meta-review of secondary studies on positive behaviour support. Further, they thematically constructed key themes for implementing and integrating positive behavioural support into organizations and across governmental departments. The purpose of this comprehensive analysis of the research literature on positive behavioural support was to provide information and possible directions for the organizational implementation and evaluation of the Australia Disability Services Commission's Positive Behaviour Framework (the document is available here). Based on this review, there was a substantive amount of evidence and research on the use of the positive behavioural approach (100's of studies over three decades). However, research on its system-wide applications were more prolific in schools (i.e., School-wide Positive Behaviour Support[142,149,150]) and more recently in residential and community-based services[151]. Based on this review, van den Akker et al. constructed an integrated theoretical model for PBS implementation at all levels of action and influence (i.e., microsystem, mesosystem, and macrosystem; see Figure 2). This integrated model summarizes how PBS is used to achieve well-being, understand challenging behaviours, and develop interventions for individual, service, and system change. The core elements include person-centeredness, the subjective, relational and objective dimensions of quality of life, the multilayered nature of services, the need for positive opportunities and the removal of restrictive practices. All other aspects of PBS revolve around these core features.

Figure 2: Integrated theoretical model for PBS implementation adapted from van den



van den Akker et al. also suggest that this integrated theoretical model may be very useful for integrating concepts from other disciplines such as organizational change, systems theory, leadership and learning into PBS theory.

Based on their review of the research literature, van den Akker et al. also raise another critical point about implementing and practicing positive behaviour support which is to explicitly name and clarify “values”. Citing Das, Ceulemans and Verhaaren, they assert that in practice values may become confused with norms (or morals) and as such, need to be made explicit as plans are developed and implemented. Das et al. also suggest values are ideals and motives that people strive for, closely related to ethics, and foundational to the adoption of the PBS approach. However, it should be noted that since this review was written, UK practitioners and researchers have identified this issue as pivotal when working with residential care workers and have developed and evaluated a values-driven behavioural training to effectively change the attitudes of front-line residential staff toward people with intellectual disability and challenging behaviours.

Positive Behavioural Support Competence and Training

Another example of training for those implementing positive behaviour support can be drawn from Denne and colleagues in the UK (there is overlap with those who authored the “Who’s challenging who” training).[114,141] Collectively, they have formed the PBS Academy UK and developed a PBS Competence Framework, PBS Standards for services and teams, as well as PBS Standards for training individual practitioners, support teams, and organizations. Additionally, the website includes a positive behavioural support information package for family members and carers to answer any questions they might have about the approach, and how to find out more including advice on training and practical resources.[114,141]

Positive Behaviour Support Implementation as Wraparound Service

Another value of PBS is that it includes the wraparound process of service delivery. The wraparound process involves bringing together the individual with ASD, family members, members of the community, and service professionals to create a person-directed plan with strategies and support to capitalize on opportunities that will meet both short and long-term goals relevant to the individual's quality of life.[144] It is a team-based approach with those close to the individual (i.e., family members, friends, and teachers) with a purpose of empowering that individual in a mutually acceptable manner. All have a role to play in the PBS wraparound approach.

The PBS wraparound approach assumes the individual with ASD and their family is central and the services are "wrapped around" them.[152] Families are accepted as equal decision-making partners and services need to be committed to least-restrictive, community-based interventions and emphasize interconnected systems.[152] PBS wraparound services break down silos and restructure how services are delivered to create a shared understanding of PBS language, theories, and perspectives among members.[152] PBS wraparound services follow the individual across settings (e.g., home and school and work) using interprofessional practices that integrates services. This creates a commitment to service delivery which is equitable for all.[152,153]

British Columbia: A Case Study in Positive Behavioural Support Wraparound Service

CBI Consultants in Vancouver, British Columbia has been providing person-centered and positive behavioural support practices since 1990.[154] Committed to full inclusion for persons with disabilities and challenging behaviour, they have developed and supported transition processes and interventions for children, youth, and young adults with intense needs. CBI offers training, consulting, and conducts evaluation and research to keep current in best practices. CBI consultants provide behavioural intervention, staff training, and transition planning services in early intervention programs, schools, family homes, residential services, workplaces, and Forensic Psychiatric facilities (an overview of CBI's continuum of service options can be found on vimeo.com; and, an example of two successful transitions from a local Forensic Psychiatric Hospital to a home in the community link to the process).[155]

Evaluation of Positive Behavioural Support

Determining the quality of positive support plans and the fidelity to which they are implemented is a critical achieving for good outcomes.[156] McVilly et al has developed a valid and reliable tool to evaluate positive behavior support plans: The behaviour support plan quality evaluation tool (BSP-QEII).[156,157] The BSP-QEII was designed to audit and assess the delivery and quality of positive behavioural services for adults with intellectual disability who engage in behaviours that challenge. The BSP-QEII can also be used as an audit tool for measuring the quality of behaviour support plan, for guiding educational activities for staff and decision-making policy-makers in community-based services for adults with intellectual disability.[156,157]

Based on this review there was very little mention of equity or any evaluation and research on the practice of equity for individuals with ASD. When delivering services, it is imperative to ensure that people can access the services, which are acceptable and helpful, affordable, and accommodating. Therefore, putting the focus on questions of disparate access and outcomes by race, ethnicity, sex, identity, and ability enforces the values and fidelity of PBS.

Summing Up: Choosing Now for A Comprehensive Approach to In-Home, Community Living for Persons with ASD

The evidence reviewed in this report shows that most people with ASD will require support in their homes, whether that home is with their families or in a community-based residential arrangement. Any move towards housing to properly support persons with ASD must, to abide by best practices and evidence, have at their foundation person-directed planning and as a core pillar of in-home supports that are focused, no matter the housing arrangement, on achieving a measurable Quality of Life framework. This person centred planning and QOL framework is particularly important to start at a young age, to assure that youth and young adults, and their families. Plans that focus exclusively on normative outcomes (e.g., living independently or full-time employment to be financially self-sustaining) should be broadened to include quality of life outcomes (e.g., self-determination, personal development, and well-being). Residential service providers and direct support staff may need to become familiar with and proficient in the evidence-based strategies that families and educators have been using to support the upcoming generation of adults with ASD.

Although supported residential living options are scarce, the importance of individuals with ASD leading the process of designing space (indoor and outdoor) to meet their unique sensory and social needs will be essential to ensure they can cope with their living environments. If no residential options are available for the foreseeable future, families and their adult children with ASD will need support in their homes and communities to be productive and healthy. Of particular concern, is the intermittent and sometimes ongoing need for positive behavioural support wraparound services. These services keep people in the community and maintain quality of life, prevent and reduce injuries, the use of restraints, hospitalizations, and long-term institutionalization.

Finally, individuals and their families need to be a part of the solution. There is also tremendous capacity in the community, among service providers, and within government. With the evidence in hand, it is time to act!

Appendix A: How many people have a diagnosis of ASD in Nova Scotia?

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 423 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 140 children (i.e., 423*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 parents and caregivers identifying the signs of ASD, receiving a referral for an assessment, availability of clinicians, and timely diagnostic services. 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. As discussed earlier, 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]

Nevertheless, the focus of this paper is 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 providing an estimate of 2,038 youth and adults 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.

Table X: Projected ASD Population in Canada, Nova Scotia and Halifax Regional Municipality (HRM)

Population	**Canada**			**Nova Scotia**			**HRM**		
Age Group	**#**	**Projected ASD Prevalence**	**% of Total ASD Prev**	**#**	**Projected ASD Prevalence**	**% of Total ASD Prev**	**#**	**Projected ASD Prevalence**	**% of Total ASD Prev**
0 to 4 years	1,898,790	28,770	5.4	42,005	423	4.5	19,795	291	4.9
5 to 9 years	2,018,130	30,578	5.7	45,980	450	5.0	20,745	305	5.1
10 to 14 years	1,922,645	29,131	5.5	45,840	428	5.0	20,000	294	5.0
15 to 19 years	2,026,155	30,699	5.8	51,260	451	5.5	22,345	329	5.5
20 to 24 years	2,242,690	33,980	6.4	56,160	500	6.1	30,225	444	7.5
25 to 29 years	2,285,990	34,636	6.5	53,730	509	5.8	30,205	444	7.5
30 to 39 years	4,617,760	69,966	13.1	103,740	1,029	11.2	53,190	782	13.2
40 to 64 years	12,203,930	184,908	34.7	341,070	2,719	36.9	143,725	2,114	35.6
65 years and over	5,935,635	89,934	16.9	183,820	1,323	19.9	63,175	929	15.7
Total Population	35,151,725	532,602		923,605	7,832		403,405	5,932	

Source: From Statistics Canada 2016 Census of Population (98-401-X2016043 and 98-401-X2016044)
Projected ASD population was calculated from PHAC's Autism Spectrum Disorders Among Children and Youth in Canada 2018
Canada's prevalence rate was 1 of 66; Nova Scotia and HRM was 1 of 68

Appendix B: Current Capacity in Nova Scotia for In-home and Residential Support Options (1998 – 2017)

DISABILITY SUPPORT PROGRAM - CAPACITY - RESIDENTIAL SUPPORT OPTIONS FROM 1998										
December, 2017										
Type of Facility	Fiscal 1998/99	Fiscal: 1999/00	Fiscal 2000/01	Fiscal 2001/02	Fiscal 2002/03	Fiscal 2003/04	Fiscal 2004/05	Fiscal 2005/06	Fiscal 2006/07	Fiscal 2007/08
Residential Care Facilities	1,354	1,336	*566	566	566	566	560	544	518	515
Adult Residential Centres	651	651	620	656	536	536	512	512	492	492
Group Homes/Developmental Residences	294	300	312	346	378	405	404	444	456	493
Regional Rehabilitation Centres	279	226	211	179	130	149	149	149	154	154
Small Options(Licensed) 3 or More Clients	912	912	*636	663	685	679	686	636	633	624
1 - 2 Person Unlicensed Homes										
Small Options - Children - (Licensed)										
Alternative Family Support/Community Residences/Associate Families	308	308	*175	178	220	220	182	183	183	193
Independent Living Support/Supervised Apartments	605	605	694	694	642	552	607	607	607	608
Direct Family Support (Children & Adults)								1600	1750	1750
Direct Family Support (Children)										
Enhanced Family Support										
Flex Individualized Funding - Independent										
Flex Individualized Funding - In Home										
TOTAL	**4,403**	**4,338**	**3,214**	**3,282**	**3,157**	**3,107**	**3,100**	**4,675**	**4,793**	**4,829**
Eff April 1, 1993 - Homes for the Aged and Licensed Nursing Homes were transferred to the DOH										
27 Nursing Homes /2118 Beds & 41 Homes for the Aged/3681 Beds										
Seniors living in Homes for Special Care under the jurisdication of DCS remained with DCS										
***Eff. April 1, 2000** - The following were transferred to DOH:										
34 Residential Care Facilities (747seniors)										
32 Community Residences (60 seniors)										
40 Small Option Homes (92 seniors)										
Adult Protection Program										
Administration of Adult In-Home Support Pgrm										
Intake,placement & case mgmt of clients in HFA/LNH										
The Senior Citizens Secretariat										
Jan., 1996 -Halifax County Regional Rehabilitation Centre(130 Beds) 5 Yr.Downsizing/Closure announced										
June 28, 2002 - Halifax County RRC Closed										
Jan., 2001 - Scotia Adult Residential Centre (140 Beds) 2 Yr. Downsizing/Closure announced										
Nov. 15, 2002 - Scotia ARC Closed										
January 2005 -Direct Family Support Program implemented										
# of clients increased as clients in other categories were reassessed, and new clients were deemed appropriate for Program										
July 1, 2006 - Bayside Adult Residential Centre Transferrred to DOH										
Feb. 6, 2012 -Small Option Homes - 3 or More Residents - Now Required to be Licensed (178 Homes - 535 Beds)										
December, 2012- Enhanced Family Support Program Introduced										
December, 2013: Breton Ability Adult Residential Centre Capacity Changed from 70 to 53 +2 (Decrease of 17 Beds)										
January, 2015- Riverview Adult Residential Centre Capacity reduced from 90 + 1 to 50 +1 (Decrease of 40 Beds)										
June, 2015 - Sunset Adult Residential Centre Capacity reduced from 115 + 1 to 71 +1 (decrease of 44 Beds)										
March, 2016 - DFSA Program converted to Flex Program - Seperated from Direct & Enhanced Family Support for Children										

June 30, 2016 - Moratorium on the length of stay in an ARC/RRC - any new placement must be considered a temporary placement

DISABILITY SUPPORT PROGRAM - CAPACITY - RESIDENTIAL SUPPORT OPTIONS FROM 1998

December, 2017

Type of Facility	Fiscal 2008/09	Fiscal 2009/10	Fiscal 2010/11	Fiscal 2011/12	Fiscal 2012/13	Fiscal 2013/14	Fiscal 2014/15	Fiscal 2015/16	Fiscal 2016/17
Residential Care Facilities	493	491	458	458	447	450	450	450	448
Adult Residential Centres	492	492	480	480	476	461	420	375	370
Group Homes/Developmental Residences	497	501	575	593	611	621	590	592	578
Regional Rehabilitation Centres	167	186	186	190	190	189	189	185	185
Small Options(Licensed) 3 or More Clients	645	638	609	534	535	543	573	589	625
1 - 2 Person Unlicensed Homes				28	26	26	27	24	24
Small Options - Children - (Licensed)				47	53	50	41	41	38
Alternative Family Support/Community Residences/Associate Families	213	215	211	199	203	203	179	172	160
Independent Living Support/Supervised Apartments	678	703	675	670	677	677	725	745	741
Direct Family Support (Children & Adults)	1895	1895	2035	2015	1959	1918	2051	**2073**	665
Direct Family Support (Children)									11
Enhanced Family Support					41	46	46	46	44
Flex Individualized Funding - Independent									1301
Flex Individualized Funding - In Home									7
TOTAL	**5,080**	**5,121**	**5,229**	**5,214**	**5,177**	**5,184**	**5291**	**5,292**	**5,197**

Eff April 1, 1993 - Homes for the Aged and Licensed Nursing Homes were transferred to the DOH
27 Nursing Homes /2118 Beds & 41 Homes for the Aged/3681 Beds
Seniors living in Homes for Special Care under the jurisdication of DCS remained with DCS

***Eff. April 1, 2000** - The following were transferred to DOH:
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Adult Protection Program
Administration of Adult In-Home Support Pgrm
Intake,placement & case mgmt of clients in HFA/LNH
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June 30, 2016 - Moratorium on the length of stay in an ARC/RRC - any new placement must be considered a temporary placement

Appendix C: Methodology

The purpose of this review is to provide evidence-based guidance on person-directed growth and support within ASD appropriate supports in housing models. There are several factors to consider when choosing the methodology, such as managing the scope of the review and timelines. The Rapid Review methodology, a research methodology outlined by the National Collaborating Center for Methods and Tools provides a timely and valid view of the evidence. A Rapid Review is a form of knowledge synthesis that follows the systematic review process and simplifies or omits components of the process to produce information in a timely way. The first step was to consult expert opinion around the landscape of the research evidence. Experts reported there are very few studies published on adults with ASD and even fewer studies published on ASD appropriate housing models. However, there has been considerable work done to synthesize and pre-appraise the gaps in the evidence.

With this limitation in mind and because the findings will be used to help determine directions for individuals' housing choices and options, and possibly provincial service delivery and policy, only the highest quality evidence could be used. The review covered peer-reviewed articles and documents available online between 2010 and 2018. Where there were gaps in the literature for certain topic areas, the review was extended to include pre-appraised syntheses published between 2000-2018 (ten years). By following the National Collaborating Center for Methods and Tools (NCCMT) Search Pyramid approach that supports efficient searches of evidence that have already been systematically synthesized. Searches start at the top of the pyramid with the most synthesized evidence documented in summaries and moves down to synopses of syntheses (e.g., descriptions of systematic reviews or meta-analyses) and syntheses (e.g., systematic reviews and meta-analyses) and single studies. Pre-appraised evidence were used first, and single studies were only used when there were gaps in published systematic reviews. As anticipated, this latter search method was mainly employed when searching for evidence related to specific understudied topics, such as supporting people with ASD who are non-verbal to make decisions about their housing options.

An array of keyword searches was used that address the continuum of ASD issues, practices, and policies as provided within a home or community context. Databases that provided pre-appraised evidence were searched first, such as the Cochrane Database of Systematic Reviews. Bibliographic databases such as PsycNET, MEDLINE, Google Scholar, and CINHAL (Cumulative Index to Nursing and Allied Health Literature) were searched for individual studies. Reference sections of relevant research were searched (i.e., backward search) and forward searches were also conducted (i.e., who cited the pertinent research). The report focused on peer-reviewed, mainly academic literature, and included some best practices documents.

Limitations

What is presented here is an overview – a skimming of the surface of the evidence as it relates to supporting individuals with ASD. It is hoped that much 'deeper dives" into some of the topics can be completed to provide for a fuller picture of the complexity of some of the issues. Consistent interpretation of different findings has also been difficult due to varied sample size, sampling procedures, differences in diagnostic criteria over time, wide range of age, differences in measures used, and imprecise and/or poor-quality data.

Appendix D: Examples of Jurisdictions using Schalock's QOL Model

Maryland, USA

The Maryland Ask Me! project conducts an annual QOL survey with the residential services who serve people with intellectual and developmental disability (I/DD).[158] They use the ASK Me! survey, developed with and by self-advocates in Maryland, and based on Schalock's (2000) eight QOL domains.[158] Self-advocates also participate as assessors and administrators of the tool.

The survey results provide organization-level averages for QOL, comparisons with previous organization-level averages, as well as comparisons with a statewide average. An annual report of the survey results provides system-level aggregate data and recommendations based on this analysis. Service providers use this information at an organizational level. The Maryland Developmental Disabilities Administration (DDA) uses the results at the systems level to measure outcomes against established evaluation indicators to inform and guide policy development in Maryland.[159,54,160]

Alberta, Canada

Alberta Human Services uses the assessment tool My Life: Personal Outcomes Index™ (POI) and people with I/DD participate as the respondents, assessors, and administrators of the survey. Services for Persons with Developmental Disabilities (PDD) use this personal outcome data to make evidence-based decisions and to compare their effectiveness with other service providers. Measuring personal outcomes is one part of a Change Initiatives project that is creating a system to measure the overall effectiveness of the program through a performance management framework. The emphasis is on the implementation and application of the findings from the personal outcome results at the organizational level to design systems which improve QOL at the local community level and provincial level for people with I/DD, including ASD.

Costs for using the POI have decreased since 2011 as surveyors have been trained and the tool is being used more broadly. An average of 890 surveys was completed annually. Costs from October 2011 to March 31, 2014: Survey administration (including hiring and training surveyors) was $1,539,459.00; survey data management and reporting were $322,450.00. Cost for POI contracts from April 1, 2014, to March 31, 2015, were for survey administration (including hiring and training surveyors) was $641,244.00; survey data management and reporting were $172,250.00.

Alberta Human Services has worked closely with Dr. Schalock and others to develop a suite of shareable processes, procedures, and quality measure standards. Information is available for self-advocates, families, and service providers in multiple formats on this website (www.humanservices.alberta.ca).

British Columbia, Canada

Community Living British Columbia (CLBC), uses the assessment tool My Life: Personal Outcomes Index™ and Schalock's QOL outcomes framework. They began the Include Me! Quality of Life Initiative in 2011 to establish an evaluation process that would improve services, systems, and the quality of life for all people who receive their services. It has been proven to be an excellent quality improvement tool, as well as a communication tool for people with a disability, service providers, and policy-makers (see this website for a detailed overview of recent and past reports www.communitylivingbc.ca).

Based on these brief examples of three jurisdictions, there is flexibility within this model and adaptability for supporting people with ASD.

Appendix E: ASD-specific Person-Centered Planning Processes

Better OutcOmes & Successful Transitions for Autism: BOOST-A

Hatfield et al. (2017) examined the effectiveness of the “Better OutcOmes & Successful Transitions for Autism” (BOOST-A™). It is an online program that supports youth on the autism spectrum to prepare and plan for leaving school. Ninety-four youth with basic computer skills and the ability to write at a grade 5 level were allocated to a control (n = 45) or intervention (n = 49) group. The intervention group used the BOOST-A™ for 12 months, while the control group participated in the traditional face-to-face transition process. Outcomes included self-determination, career exploration and planning, quality of life, environmental support, and self-determination. Results indicated the BOOST-A group differed from the control group in three outcome areas (i.e., self-determination at home, transition-specific self-determination, and career exploration). Results support the BOOST-A™ planning process in that it can enhance some career-readiness outcomes, however for some youth on the spectrum, perhaps for those with intellectual disability or who do not read or write, other types of in-person planning methods may be more appropriate.

Collaborative Model for Promoting Competence and Success: COMPASS

Ruble et al. (2018) developed the Collaborative Model for Promoting Competence and Success (COMPASS) model and evaluated it in a randomized controlled trial with 20 special education teachers and transition-age youth with ASD.[72] The teachers were randomized into a COMPASS student group (*n* = 10) or a comparison student group (*n* = 10). The implementation of COMPASS was individualized. A consultant coached each teacher to support a student with ASD, and their family members, through a transition planning process that identified post-high school goals, where the student would like to live, possible daily activities, community participation, and friendships. Evaluation of the implementation showed that the consultant fidelity to the process was high. Teacher adherence to the process was low at first and improved over time. Results showed that Individualized Education Program outcomes were higher for the COMPASS group compared to the control group - 67% of students who received COMPASS met their goals compared to 18% of those in the control group. The overarching benefit of the COMPASS process was that it provided opportunities to adjust for the barriers and the students through evidence-based consultation activities. Given the breadth of the spectrum, processes must be adaptable and shift to accommodate different communication styles and various types of life plans. [72]

Appendix F: Evidence-based Practice Definitions

Evidence-based Practice	Definition
Antecedent-based intervention (ABI)	Arrangement of events or circumstances that precede the occurrence of an interfering behavior and designed to lead to the reduction of the behavior.
Cognitive behavioral intervention (CBI)	Instruction on management or control of cognitive processes that lead to changes in overt behavior.
Functional behavior assessment (FBA)	Systematic collection of information about an interfering behavior designed to identify functional contingencies that support the behavior.
Functional communication training (FCT)	Replacement of interfering behavior that has a communication function with more appropriate communication that accomplishes the same function. FCT usually includes FBA, DRA, and/or EXT.
Self-management (SM)	Instruction focusing on learners discriminating between appropriate and inappropriate behaviors, accurately monitoring and recording their own behaviors, and rewarding themselves for behaving appropriately.
Social narratives (SN)	Narratives that describe social situations in some detail by highlighting relevant cues and offering examples of appropriate responding. Social narratives are individualized according to learner needs and typically are quite short, perhaps including pictures or other visual aids.
Technology-aided instruction and intervention (TAII)	Instruction or interventions in which technology is the central feature supporting the acquisition of a goal for the learner. Technology is defined as ‘‘any electronic item/equipment/application/or virtual network that is used intentionally to increase/maintain, and/or improve daily living, work/productivity, and recreation/leisure capabilities of adolescents with autism spectrum disorders’’ (Odom et al. 2014a)
Prompting (PP)	Verbal, gestural, or physical assistance given to learners to assist them in acquiring or engaging in a targeted behavior or skill. Prompts are generally given by an adult or peer before or as a learner attempts to use a skill.
Reinforcement (R +)	An event, activity, or other circumstance occurring after a learner engages in a desired behavior that leads to the increased occurrence of the behavior in the future.
Differential reinforcement of alternative, incompatible, or other behavior (DRA/I/O)	Provision of positive/desirable consequences for behaviors or their absence that reduce the occurrence of an undesirable behavior.
Response interruption/redirection (RIR)	Introduction of a prompt, comment, or other distracters when an interfering behavior is occurring that is designed to divert the learner’s attention away from the interfering behavior and results in its reduction.
Extinction (EXT)	Withdrawal or removal of reinforcers of interfering behavior to reduce the occurrence of that behavior.

Appendix G: A Canadian Jurisdiction with Practice Standards for DSPs

Canadian Jurisdiction: Ontario's Practice Standard for DSPs

The Ontario Ministry of Community and Social Services (MSCC) has adopted competencies and developed training to align DSP practice with the *Services and Support to Promote the Social Inclusion of Persons with Developmental Disabilities Act* passed *in* 2008. In 2010, the MSCC developed core competencies for all disability support service providers in partnership with the Provincial Network on Developmental Services (i.e., Direct Support Professionals, Direct Support Supervisors, Specialized Support Workers, Clinical Specialists, Managers, and Directors). In 2013, the MSCC surveyed direct support professionals to better understand the work experiences in Ontario's developmental services sector.[161] The survey was completed by 2,721 respondents who answered questions about job satisfaction, experiences of burnout and occupational stress, organizational commitment, perceptions of organizational support, prosocial motivation, and a range of other demographic information. The most significant finding was that over 96% of DSPs reported high satisfaction with their work in the sector. DSP's reported having positive relationships with the people they support and with their co-workers. Good organizational support was associated with less burnout and stress. However, the findings also pointed to a key concern, in that "the desire to do good can result in employees feeling emotionally exhausted when service idealism conflicts with the reality of service constraints".[161(pi)] The results suggested that focusing on fundamental human resource practices such as organizational communication and training would have a variety of positive effects on both the employment relationship and the support relationship in the sector. In 2014, MSCC launched an initiative to develop training for direct support professionals based on the core competencies and the needs within the sector (see below).[162] These include modules on a number of topics covered in this report, including: developmental disabilities with concurrent mental health disorders; values and person-centered planning; positive support and applied behaviour analysis; health and wellness; health and safety; and general professional development.

Ontario's Practice Standard for DSPs

Module	Topic
Developmental Disabilities	Concurrent Mental Health Disorders (Dual Diagnosis) Introduction to Developmental Disabilities
Values and Philosophies	Rights Values and Attitudes Quality Assurance Measures Introduction to Core Competencies Person Centered Planning
Interventions	Crisis Interventions Providing Positive Support / Applied Behaviour Analysis
Health and Wellness	Nutrition Aging Relationships / Sexuality Bereavement / Grief / Loss Preventing and Responding to Abuse Augmentative Communication Medication Administration and Pharmacology
Health and Safety	First Aid / CPR / AED Workplace Hazardous Material Information Systems Fire Safety Lifts / Transfers and Back Care Safe Food Handling Violence in the Workplace Infection Prevention and Control
Professional Development	Teamwork Documentation Communication Conflict Management Diversity Training Community Development and Relationships Family Relationships Leadership

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