Ottawa Adult Autism Initiative (OAAI)

Results of a Community Consultation on Needs and Gaps in Service for ASD Adults in the Ottawa Area

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We are extremely grateful to the participants in the OAAI community consultation, including ASD adults, family members and allies, and professionals who work with ASD adults. Their extensive input has put shape, colour and texture on the "snapshot" of current and future needs of the ASD adult community in Ottawa.

On behalf of all involved in this initiative, we thank and recognize the Ontario Trillium Foundation for its generous Seed Grant funding for this project.

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Executive Summary

The community consultation conducted by the Ottawa Adult Autism Initiative (OAAI) endeavored to better understand the ASD adult community in Ottawa – specifically, ASD adults, family members and allies (including those who are primary caregivers) to ASD adults, and professionals who serve the ASD adult community. Consultation input was received from 442 individuals through surveys, multiple small group consultations and individual interviews, and community validation sessions completed in 2020 and early 2021. The consultation has captured an initial community snapshot and greater understanding of the diverse needs and viewpoints of those in and close to the ASD adult community in the Ottawa area.

Findings from survey responses, small group discussions, individual interviews and community validation sessions tell us that the ASD adults in Ottawa have a very diverse profile and equally varied needs. They face many barriers to achieving the lives they want to live. Overall, finding tell us that ASD adults want to be busy outside the home, be healthy both physically and mentally, have close relationships and a secure future. As a group and as individuals, they face numerous and overlapping barriers that systemic/structural barriers, attitudes of society at large and the very organizations and care providers they need, as well as physical barriers.

A maze of inter-related barriers

For **ASD adults**, access to stable financial resources through employment, or through qualifying for disability benefits are simply not an available option to most. These barriers “support” additional barriers to ASD adults meeting other essential needs, such as access to housing, support to live as they wish, better physical and mental health care and being engaged in social and recreational activities they enjoy. Broadly speaking, ASD adults face barriers in a society that is unaccepting of them, with few prospects to freely access opportunities they want and the help they need – in particular with respect to mental health, financial security (including employment) and housing that meets their needs. COVID-19 has exacerbated their challenges by making the world even more inaccessible.

Family members and allies echo the frustrations of the ASD adults in their lives. They often find themselves in the position of bridge between their ASD loved one and the rest of the world. They, too, have severely restricted access to the resources they need for the ASD adult in their life to live as full a life as possible and, importantly, for them to also live a full life. Many family members and allies are exhausted, overwhelmed and extremely worried about the future—especially a future where they are no longer alive to support the ASD adult in their lives. They feel unsupported and unsure of where to turn for help.

Professionals recognize that they have an important contribution to make to the lives of ASD adults by way of enabling and/or providing skill-building, therapies, education, mental health support, social and recreational opportunities, and research, among others. They know that they are a scarce resource and not well-connected to all the needs in the broad landscape of needs of ASD adults and their families/caregivers. They recognize that they have a limited capacity to serve ASD adults who have more complex needs and challenges, including those who are less verbal or non-verbal. They appreciate that many ASD adults face financial barriers that render their services, even at low hourly fees, beyond reach.

Some bright spots on an overall challenging landscape

While the broad picture for ASD adults reflects significant difficulty and, for families, overwhelm and real fear about the future, the engagement from the ASD adults, family members/ allies and professionals in Ottawa highlights the collective vision to do better. Each group has their own needs and contributions – many of which are operating in silos around Ottawa.

It is clear that a comprehensive network to bridge fragmentated services and supports, to fill gaps in services that don't exist and/or do not meet needs, and to connect people, supports, services and resources are required to achieve that collective vision. This clarity arises directly from the evidence collected. Despite a pandemic which has shut down most of the world, OAAI managed to receive 442 individual inputs into the consultations via the survey, online small group consultation and interviews. This is an amazing feat. The success of this consultation has led to an enormous volume of feedback. The first step is this initial report but there is enough data to inform the development of a city-wide network for the years to come.

Seven Themes and Overall Considerations for Next Steps

Consultation findings point to some clear directions and next steps in the development of a comprehensive network of services and supports for ASD adults in Ottawa, as set out throughout this report. These considerations are set out following a summary of the key themes arising from the consultations.

Theme 1: ASD adults' connection to support agencies/organizations is limited and services available for ASD adults are not aligned to meet individual needs.

Theme 2: Many ASD adults want to participate in paid or voluntary work, and/or study and learning opportunities, yet opportunities are limited and come with major challenges.

Theme 3: To better support their physical and mental health, above all, ASD adults need professionals across diverse services who understand autism.

Theme 4: ASD adults need help, support and tools to be more involved in important life decisions.

Theme 5: For a secure future, ASD adults need financial resources, a personal support network, a plan and a home – fear about the future is a major source of emotional pain for family members/allies.

Theme 6: An individualized housing plan is paramount to ASD adults, family members/allies and professionals – for a better life now and in the future. Barriers to housing seem insurmountable and overwhelming.

Theme 7: Professionals provide a diverse yet inadequate number and array of supports and services to ASD adults. Professionals mostly serve verbal ASD adults and those with less complex needs.

Services, alignment of services with needs, navigation

- **Streamlined access** to services and more **flexible eligibility criteria** to better reflect the needs, priorities and capacities of ASD adults. This will require collaborating with others to advocate for funding to **align with needs**, and for encouraging and educating professionals across service areas to **fill gaps and evolve services** to meet needs. Collaborators need to include established organizations to provide capacity and governance, advice and connections (for example, Autism Ontario).
- Tools for **system-wide navigation** of services and supports that enable easy, transparent and faster access to services and supports.
- Supports and services that **align with the specific needs of non-verbal/less-verbal ASD adults and older ASD adults**, and further efforts to **understand the priorities of ASD adults with complex needs** (including those with dual/multiple diagnoses).
- Mechanisms to **identify and deconstruct systemic and other barriers** to employment and financial autonomy for ASD adults.
- Better information on the **needs and priorities of** ASD adults under-represented in consultations: **Francophones, LGBTQA2S+, rural dwellers, Indigenous people, newcomers, visible minorities**.

Awareness and knowledge

- A strategic plan to improve community and funder understanding of how employment/volunteerism contributes to both **socially valued roles** for ASD adults, and to **financial autonomy**.
- A dedicated **information/education agenda for health professionals and other professionals** involved in the health and well-being of ASD adults (e.g., lawyers, financial advisors) so they better meet the needs of ASD adults.
- A strategic communication/information plan to **promote better understanding of autism across the community** to contribute to **Ottawa becoming an autism-friendly city**.

Support a secure future for ASD adults by creating a secure present

- Supports and tools for **ASD adults to play a strong role in making and communicating important life decisions**, in recognition that decision making is critical to autonomy. This calls for tailored approaches to address complex and evolving needs of non-verbal/less verbal and older ASD adults.
- That suitable, stable, affordable **housing is a right** and essential to the future security of ASD adults. This calls for building awareness/ understanding among housing providers and funders of the importance and **value of supporting housing options** for ASD adults. It also calls for better tools to support ASD adults and their family members/allies to easily develop **individualized housing plans**.

I Introduction

About this Initiative: Background and Context

Autism Spectrum Disorder (ASD) is a lifelong neurological disorder that affects 1 in 66 children and youth in Canada.[1] Assuming the same prevalence in adults, there are an estimated 14,500 adults on the autism spectrum (referred to throughout this report as ASD adults) in Ottawa, Canada's fourth largest metropolitan area with a population of 1.25 million people.

The availability of resources, services and support continuing into adulthood can contribute to the success of a person an ASD adult in many areas of life. However, there are many barriers to access to needed supports – among them, the lack of a coordinated, comprehensive network that connects services and supports for ASD adults.

Supported by a seed grant from the Ontario Trillium Foundation, the Ottawa Adult Autism Initiative (OAAI) undertook a community consultation initiative to better understand the Ottawa ASD adult community which includes adults on the autism spectrum, their family members and allies (some of whom are caregivers to ASD adults), as well as the professionals who work with ASD adults. Specifically, the consultation sought to gain an understanding of the supports and services that exist and work well for the Adult ASD community as well as the gaps and barriers that affect quality of life and the ability of ASD adults to access to opportunities for the good things in life. The initiative consulted the local community through surveys, small group consultations and individual interviews, and attempted to reach specialized groups within the adult ASD community with diverse needs and viewpoints, including women, sexual/gender-diverse adults, Francophones and ethnic minorities.

The OAAI community consultation initiative is a grassroots-led to help inform the creation of a comprehensive supports and services network in Ottawa.

Approach and Methodology

The OAAI formed a steering committee that includes ASD adults from the community, professionals who work with ASD adults and family members and allies (some of whom are caregivers for ASD adults). A sub-group of the OAAI Steering Committee formed a working group to recruit external consultants to design and conduct the community consultation. The consultants worked collaboratively with the OAAI Steering Committee, while maintaining an arm's length relationship to ensure objectivity of data collection, analysis and presentation of results. The Steering Committee, and particularly its working group, had significant input to the consultation design and implementation at all key stages of the initiative. The working group collaborated with the consultants to design and co-create on-line surveys and interview

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[1] https://www.canada.ca/en/public-health/services/publications/diseases-conditions/infographic-autism-spectrum-disorder-children-youth-canada-2018.html

questions, and to determine and revise (due to COVID-19) the small group and individual interview components of the consultations. [2] This group was primarily responsible for recruiting participants to surveys, group and individual interviews. The broader Steering Committee also participated in review of the analysis of findings and the data/findings validation process.

The consultants and working group adopted an approach of inclusivity. For example, the survey for ASD adults was available in both official languages as well as in an image-based format (in both languages) to reach adults with less conventional communication profiles.

The consultants conducted a limited review of literature focused on autism supports and services, with an emphasis on potential promising practices for delivery of services and supports.[3] This was supplemented by a review that the OAAI team undertook (2019) to explore existing service models among established organizations in preparation for community-wide consultation.[4] The two key aspects that shape the scope of this review included barriers and unique issues facing those accessing autism services and potential promising practices for service delivery.

Surveys

In total, eight (8) surveys were designed and implemented with the goal of collecting qualitative and quantitative information from three target groups:

1. Four surveys with the same content for ASD adults (one word-based survey, one image-based survey, and an English and French version of each of the word-based and image-based surveys). Note that ASD adults were invited to complete one of these surveys – for those unable to complete the survey on their own, caregivers were invited to complete the survey fully or partially for an ASD adults, and to provide responses as if the ASD adult were responding directly to the survey.)
2. Two surveys (one English, on French) for family members/allies of ASD adults, with respondents asked to answer the questions ABOUT (not for) the ASD adult they care for.
3. Two surveys (one English, one French) for professionals who work with ASD adults.

The surveys were open for five months (July 17, 2020 to December 17, 2020). The surveys were promoted widely by the Steering Committee, and community organizations were asked to share them widely with their communities. In other words, a "snowball sampling" method was used to reach as many members of each survey group as possible.

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[2] One working group member developed a comprehensive series of images for the image-based version of the survey for ASD adults, which aligned fully with the companion word-based survey for ASD adults.

[3] A review of what other, similar grass-roots organizations had done to fill service gaps/develop a network of Services was conducted by a member of the Steering Committee prior to the OAAI initiative—that work informed the goals of the OAAI community consultation as set by the Steering Committee.

[4] Report on Hub Research, Margaret Janse van Rensburg (2019)

Interviews and small group consultations

Small group consultations (11 groups) and individual interviews (16) were held with stakeholders from the three target groups (ASD adults, family members/allies, and professionals). The consultants (with input from the OAAI working group) created an interview guide tailored to the group/individuals being consulted to probe some key survey findings and to add both context, insights and more detail to survey results. The small group and individual consultations were led by the consultants with an OAAI Steering Group member present in small group consultations to provide technical support and/or emotional support to participants, if required.

Community validation sessions

Two group sessions were held (13 people in total) with participants in the consultations to validate themes and considerations developed from the survey, small group discussions and individual interviews, and prior to the consultants finalizing the report.

Limitations

The results of the consultations have a number of limitations to be taken into consideration including participant sampling, COVID-19 and a number of biases.

Participant Sampling

Participants who responded to the survey or participated in the small group and/or individual consultations were not randomly selected. Participants self-selected to participate, were connected to the autism community in some way that led them to the consultation (including through the snowball sampling noted above), were able to read and answer the survey/ interview question questions in English or French and had access to the internet (for the survey and/or small group consultations) or the telephone (some one-to-one interviews).

COVID-19

In mid-March 2020, community restrictions on in-person contact as a result of COVID-19 were implemented in Ottawa. In response, the Working Group, funder and consultants put the initiative on hold for three months. Re-launch of the initiative included a revised plan for timing and format of consultations. Specifically, the surveys were launched later than initially planned and remained open for longer than initially planned. Plans for in person consultations (interviews, small group consultations and community validation) were replaced with online consultations. Online consultations might have restricted the number of people in the ASD community who were comfortable or able to do this work online. Additionally, adults on the autism spectrum and the autism community were likely disproportionality affected by COVID, generating considerable stress. Again, this may have restricted the capacity for some members of the adult ASD community to participate. In addition to participation being restricted, COVID19 may have influenced the answers to the questions, skewing them as respondents reflected on their lives in the shadow of a worldwide pandemic.

Self-reported data
The responses are self-reported therefore cannot be verified and limited by memory bias (e.g., memory bias, attribution or exaggeration). The responses are to be taken at face value.

Acquiescence and Social desirability bias
ASD adults may be prone to certain biases as a result of past training, therapies, traumas or life experiences. These biases might include “yes-saying” or the friendliness bias which occurs when respondents tend to agree with and be positive about whatever is being presented; social desirability bias which involved responding to questions in a way that they think will lead to being accepted or liked.

Professional and personal bias
As a grassroots initiative, the project’s steering committee includes individuals with a role (professional and personal) in the adult ASD community. They may have brought professional and personal biases to influence the project. To reduce potential bias, the steering committee intentionally engaged independent consultants to design the consultation and collection tools, conduct the consultations, analyze and synthesize results and develop considerations and potential next steps.

II Consultation Participants

Survey respondents

Across the six surveys (including English and French versions) created, disseminated and promoted widely in the Ottawa area, the number of responses varied. (See Figure 1). Clearly, the number of French-language survey completed (across all categories) is extremely low, relative to the proportion of the Ottawa population that say that French is the language they speak most often at home (9% as of 2016, as calculated from data in the Census Profile, 2016 Census for the City of Ottawa).[5] It is possible that some individuals who completed an English-language survey speak

Figure 1: Total useable responses from all sources

Target Group	Survey Language	Responses	Total Responses
Surveys			
ASD adults (or caregivers, for adults who could not respond on their own)	English	103	107
	French	4	
Family members/allies of ASD adults (responding about, not for an ASD adult)	English	156	165
	French	9	
Professionals who work with ASD adults	English	74	75
	French	1	
Small Group Consultations (9 English, 1 French)			66
Individual Interviews (English)			16
Community Validation Sessions (2 English)			13
Total useable responses			**442**

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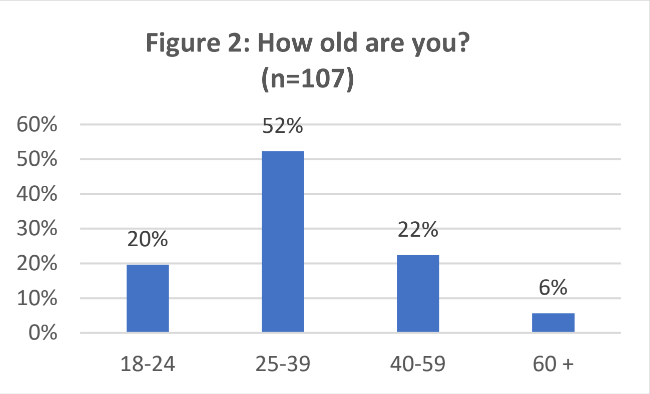
[5] Statistics Canada, 2016 Census Data: Census Profile, City of Ottawa: https://www12.statcan.gc.ca/census-recensement/2016/dp-

French most often at home. This low number of French-language surveys completed across all groups calls for further investigation and development of means to reach/understand more about this group.

ASD adult respondents range from young adult to middle age, with few seniors

A total of 107 ASD adults provided useable responses[6] to the survey in either the word or image-based format, in English or French. Over one half of ASD adult survey respondents (52%) are in the 25-39 years old bracket, with almost one quarter in each of the next younger age group (20% are 18-24 years old) and next older (22% are 40-59 years old). A small proportion (6%) are in the 60+ bracket. (See Figure 2)



The majority of respondents identify as women (44% of 107 respondents) or men (39%), with 14% identifying as genderqueer or non-binary. Only 1% specified another identity, and 2% chose “none of the above” (2-spirit, demi girl, genderfluid and human).

Other highlights include:

- Most (79% of 107 who answered this question) ASD adult respondents completed the survey themselves—15% had help and 6% had a caregiver complete it for them.
- Three quarters (74%) completed the image-based survey format (instead of the word-based survey format).
- When asked to choose from a pre-set list of groups they identify with, one quarter (23%) identify as LGBTQA2S+, 20% as “other,” and gave a range of identifiers, including disabled, mixed ancestry/specific country affiliation, neurodivergent, poor. A small proportion (12%) say they are a visible minority, 10% are Francophone, 7% live in rural area, and a very small proportion (3% each) say they are newcomers or Indigenous.

Most ASD adult respondents and ASD adults described by family members/allies are verbal

The vast majority of adult respondents report that they are able to talk “a lot” (83% of 106 respondents). A much smaller proportion report being able to talk “a little” (15%) and a very small proportion report that they are “not able to talk” (2%). When asked to choose from a prepared list other ways they communicate, most respondents identified typing (92%) and writing (81%), along with drawing (35%) and pointing to pictures or words (24%) – with sign language identified by 6%. Other ways of communicating reported by respondents include gestures, hand motions, mime/acting, playing piano and singing, and learning signing.

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[6] Useable responses include all responses that provided any responses beyond the demographic questions. In other words, if a survey response only included demographic information, it was excluded from the useable responses.

Results of the family member/ally survey (which captured the views of family members and allies about—not for—an ASD adult) show that a somewhat smaller but still significant proportion of ASD adults referred to in this survey are able to talk: 66% of respondents say the ASD adult they refer to is able to talk “a lot,” 22% say the ASD adult they refer to can talk “a little,” while 12% are responding about an ASD adult who is “not able to talk.” Family members/allies report other ways that ASD adults communicate, including typing or using sign language (67% of 165 respondents for each), writing (62%), drawing (33%) and pointing to pictures or words (18%). (See *Snapshot #5: Low/non-verbal ASD Adults*, page 45)

Two thirds of ASD adult respondents were diagnosed by a doctor, most as children

Whether diagnosed by a doctor as a child (46% of 107 respondents) or as an adult (23%), most respondents report that they received a diagnosis from a doctor. Over one quarter (26%) of ASD adult respondents identify that they are “self-diagnosed”. Another 5% chose offered other information, including other diagnoses (possibly in addition to ASD, and including ADHD, OCD) and mentioned more specifics about when they were diagnosed, or who helped them with a diagnosis. Family member/allies report that ASD adults whom they responded about are far more likely to have been diagnosed by a doctor (98%), with the vast majority (89%) receiving that diagnosis as a child. Only 2% say that the ASD adult they are responding about is “self-diagnosed.”

Family member/ally of ASD adults survey respondents

A total of 165 individuals who are a family member or ally of an ASD adult provided useable responses to a survey designed specifically for this group, in English or French. These respondents answered questions about an ASD adult – not for that person. Note that three quarters (72% of the 159 family members/allies) identify that they are the primary caregiver for the ASD adult they describe in the survey.

Professionals who support ASD adult survey respondents

A total of 75 professionals provided useable responses to a survey developed specifically for this group, in English or French. (See also page 31 for more information about this group)

Small group and individual interview participants

A total of 10 small group consultations (66 people in total) were held during the data collection period (including one Francophone group of 8 individuals), as well as 16 individual interviews. Both the small groups and the individual interviews included ASD adults, family members/allies, caregivers and professionals. Similarly, the two community validation sessions involved 13 participants from across consultation participants who provided feedback on near-final themes and considerations.

III Core Themes, Findings and Recommended Actions

Theme 1: ASD adults' connection to support agencies/organizations is limited and services available for ASD adults are not aligned to meet individual needs.

Summary of Findings

ASD adults connect to a few agencies/organizations that offer services to this population

About one third (36% of 107 ASD adult respondents) say they are connected to an agency or organization that supports ASD adults. Over one half (56%) say they are NOT connected to such an organization, while 8% say they don't know if they are connected.

A closer look at ASD adults aged 40 years and older (n=30) show that they are somewhat less connected to agencies and organizations (than all ASD adult respondents); just over one quarter (27%) say they are connected to an agency or organization and 70% say they are not connected. (See *Snapshot #6: ASD adults 40+ years*, page 50)

Of the 36% ASD adult respondents of all ages who say they are connected to an agency and the 8% who don't know if they are connected, ASD adults chose from a pre-set list of agencies most often: March of Dimes (23%), Service Coordination (16%), Citizen Advocacy of Ottawa/ABLE2 (13%), and LiveWorkPlay (12%).[7] (See also Figure 3).

Figure 3: Agencies/ organizations ASD adult is connected to	**ASD adults (n=61)**		**Family members/ allies (n= 102)**	
	#	**%**	**#**	**%**
March of Dimes	14	23%	52	51%
Service Coordination	10	16%	42	41%
Citizen Advocacy of Ottawa/Able2	8	13%	25	25%
LiveWorkPlay	7	12%	21	21%
WAVE (Dovercourt CC)	5	8%	19	19%
Algonquin College	4	7%	17	17%
Y's Owl Maclure Co-op Centre	3	5%	11	11%
Causeway Work Centre	2	3%	10	10%
OCAPDD	2	3%	9	9%
Christian Horizons	1	2%	6	6%
Spectrum Insights	1	2%	6	6%
Tamir Foundation	1	--	5	5%
L'Arche Ottawa	0	--	5	5%
Main Street Community Services	0	--	4	4%
Ottawa Foyers Partage	0	--	4	4%
Ottawa Independent Living RC	0	--	4	4%
Ottawa Rotary Home	0	--	4	4%
Ottawa-Carleton Lifeskills	0	--	3	3%
The Space	0	--	3	3%
Total Communication Environment	0	--	3	3%

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[7] Service Coordination and March of Dimes have distinct functions as the gateway to funding and subsidies and through which funding flow, which likely explains why they are the top used (but also the importance of recognizing the number of people who are not connected even to the two primary agencies for MCSS services and supports.

When asked to name other (not listed) organizations that support them, another 13 agencies were named, including Acorn (3 respondents), and others identified by one or two respondents.

Family members/allies say ASD adults have more extensive connection to agencies than do ASD adults respondents

Responses from family members/allies who answered the question about whether the ASD adult they responded about is connected to an agency/ organization that supports people on the autism spectrum, show a different picture: over one half (57%) of respondents say the ASD adult they describe is connected to an agency/organization that serves ASD adults. Family member/ally respondents were more likely than ASD adult respondents to identify connections to agencies in the same pre-set list. (See Figure 3)

Non-verbal/low-verbal (NVLV) ASD adults, as reported by family members/ allies, are more connected to agencies and organizations (67% say they are connected), with 26% not connected and 7% don't know if they are connected.

Family members/allies also identified connections with other agencies including Being Studio (4), Riverview Developmental Services (3), Valor and Solutions (3), AISO – Association pour l'intégration sociale d'Ottawa (2), Bairncroft (2) and Destiny's Way (2). Another 21 were listed by one respondent each. Across the responses from all groups, additional agencies mentioned are possibly duplicates of those listed or identified – with names slightly different and/or sub-programs of an agency listed.

Figure 4: How are you served by ASD-supportive agencies/ organizations?	**ASD adults (n=46)**	**Family members/ allies (n= 99)**
	%	**%**
Social/recreational activities	48%	61%
Employment supports	37%	32%
Financial support/funding	30%	49%
Advocacy	15%	25%
Educational support	11%	12%
Housing support	9%	16%
Supported independent living	7%	14%
None of above	17%	12%

ASD adults primarily use agencies for social/recreation, employment and financial support

When asked about how they were being served by agencies/organizations that supports people with ASD, most of the 46 ASD adults who responded to the question identified social and recreational activities (48%), employments support (37%) and financial support (30%), with smaller proportions citing advocacy, education, housing and independent living support. (See Figure 4) Among the other services respondents access are support with group home day use, ODSP, mental health, communication and workshops.

Family members/allies reporting about an ASD adult point to a similar pattern, with social and recreational services used most extensively (61% of 99 respondents), followed by financial support (49%), employment support (32%) an advocacy (25%), and a smaller proportion citing housing, supported independent living, and educational support. Among other services mentioned are day programs. These respondents were more likely to identify supported independent living services (14%) than ASD adults who answered (7%).

A closer look at services accessed by NVLV ASD adults as reported by family members/allies show that two thirds (62% of 42) receive financial support/funding, with one half (48%) receiving social and recreational supports. A much smaller proportion receive other supports including advocacy (21%), housing (21%), employment support (14%), supported independent living (10%) and educational support (10%). For the 12% who receive "none of the above," the most frequently mentioned type of service (3 respondents) is "day program."

Considerations and Conclusions Related to Theme 1

Findings that align with Theme 1 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

Theme 1: ASD adults' connection to support agencies/organizations is limited and services available for ASD adults are not aligned to meet individual needs.

- **Eligibility for government funded supports and services from local agencies and organizations is complex and eligibility is often a barrier to accessing needed supports.** Many ASD adults do not qualify for supports and services funded by the Ontario Ministry of Children, Community and Social Services (MCCSS), through Developmental Services Ontario (DSO). Eligibility for support from local agencies requires an ASD adult to qualify through DSO with a diagnosis of a developmental disability, which is not always the case for ASD adults.
- **The difficulty in finding appropriate services and supports from an array of organizations with offerings that often do not aligned with specific needs and interests is exacerbated by some broader systemic realities**. Currently, lack of access to information, evolving needs for information and services, an abundance of misinformation and the need for time, patience, knowledge and persistence to navigate the "system" are all barriers to ASD adults successfully accessing services they need.[8] In Ottawa, there are disconnected services available, rather than a "system" of comprehensive and coordinated services and supports. The role of system navigator could support ASD adults to "mine" existing services and to more fully navigate a more comprehensive system of services, once in place.
- **As a whole, local agencies and organizations may not be responding to the priority needs and interests of the ASD adults they serve.** For example, social and recreation activities, while critical to well-being, are offered widely. Yet results of the community consultation identifies that needs and interests of ASD adults, their family

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[8] Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

members/allies and professionals is focused more other needs, such as on suitable and individualized housing plans and supports that facilitate independent living. This points to the need for building awareness and advocating for service organizations to align with needs and priorities of ASD adults. Design and development of a comprehensive network must include approaches to encourage a community-wide shift to align the priorities of the local agencies and organizations to the proprieties of Adults with ASD.

- **Further work to identify the services and supports to meet the needs of ASD adults who are non-verbal/less-verbal (NVLV) and those who are aged 40+ years.** These two groups have specific service need profiles (as per consultation results). Service providers may not be taking into consideration autism over the life course and changing needs of adults as they age. Moreover, they may not consider the needs of NVLV adults, which may take time, effort and a particular skill set to determine. Agencies are likely not sufficiently funded to support the continuous re-evaluation of and adaptation to priorities as required by these two groups. Again, awareness-building and advocacy are required among current service providers that support ASD adults, as well as the broader community of services providers in areas such as housing, employment, education, and must be part of the efforts of a future network
- **Investigation into potential network models could include various versions of a "hub-and-spoke" network.** (See Appendix B: Promising Practices in Autism Support and Service Delivery: Scan of Literature) A hub-and-spoke model holds particular promise in bridging the highly fragmented landscape of supports and services in Ottawa and the enormous diversity in the ASD adult community. While there is no one set definition of hub and spoke models, they represent a variety of service delivery models arranged around clusters, satellites, and networks.[9] Such a model could, for example, see a set of core services as the hub, with secondary (and possibly specialized) services as the spokes. The current research outlines the benefits of this interdisciplinary model that include: consistency, efficiency, quality, enhanced coverage and agility.[10]

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[9] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature

[10] Elrod, J. K., & Fortenberry, J. L. (2017). The hub-and-spoke organization design: an avenue for serving patients well. *BMC health services research*, *17*(1), 457.

Theme 2: Many ASD adults want to participate in paid or voluntary work, and/or study and learning opportunities, yet opportunities are limited and come with major challenges.

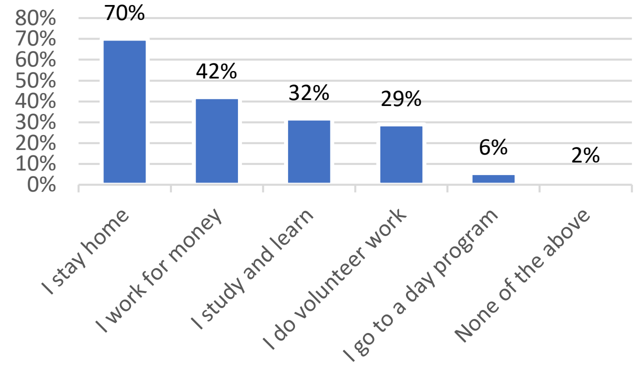
Summary of Findings

A majority of ASD adults spend most of their days at home – and not all feel good about how they spend their time

Less than one half of ASD adults (44% of 107) feel good (36%) or excellent (8%) about how they spend their day. One quarter (25%) feel not good (22%) or terrible (3%).

Over two thirds of ASD adults (70% of 107 respondents) report spending most of their time at home, with family members/allies reporting about an ASD adult saying the same (71% of 163 respondents). Results show that three quarters (76%) of NVLV ASD adults spend most of their time at home, as do two thirds (67%) of ASD adults over age 40.

Figure 5: How do you spend most of your time during the day? (n=107)



In addition to or instead of staying at home, ASD adult respondents (and family members/allies who responded about an ASD adult) say they work for money (42% of ASD adults, 49% of family members/allies), and/or they study/learn (32% and 20%) and/or do volunteer work (29% and 10%). A small proportion (6% and 20%) go to a day program. (See Figure 5)

Survey results show that NVLV ASD adults are much more likely than the general population of ASD adults to spend their days in a day program (36% for NVLV ASD adults, compared to 6% of the general ASD population surveyed).

Among other activities named by ASD adults are: pursuing hobbies, looking for employment, housework/outside work, parenting, and social activities, exercise, shopping. A few identify difficulties (COVID-19 causing cancellations of school, work, social, leisure, volunteer activities), human rights violation, mental health issues and systemic issues that are barriers to engaging in society as they would like to. Family members/allies list: developing a home business, dog-walking, hanging out at stores, riding the bus, playing video games, managing apartment, look for work. Of note, several comments (3) include “hospital” as how the NVLV group spends most of their time during the day.

Over three quarters (77%) of ASD adults say that there is something stopping them from spending time the way they want. Barriers chosen from a pre-set list include money (68%), help to be less anxious (60%), help to do what they want (59%), places that are not too crowded (51%) or loud (47%), transportation (48%), and skills (40%).

Figure 6: How ASD adults spend time during the day, want to spend time (according to ASD adults) and could well spend time (family members/allies)

Activities	**How ASD adults spend time**		**How ASD adults want to/could well spend time**	
	ASD adults (n=107)	**Family members/ allies (n=163)**	**ASD adults (n=106)**	**Family members/ allies (n=163)**
Spend time at home	70%	71%	45%	28%
Work for money	42%	26%	73%	58%
Study and learn	32%	20%	50%	42%
Volunteer	29%	10%	52%	50%
Day program	6%	20%	N/A	N/A
None of above/don't know	2%	1%	3%	1%
More activities	N/A	N/A	72%	N/A
Social/recreational activities	N/A	N/A	N/A	79%

Most ASD adults stay at home during the day—most want to do something else as well and/or instead

When asked to choose from a way they would like to spend their daytime hours, ASD adult responses showed a marked difference between how time is actually spent, and how respondents *would like to spend it*.

For example, (and see Figure 6):

- 70% spend time at home – 45% *want* to spend time at home.
- 42% work for money – 73% *want* to work for money.
- 30% study and learn – 50% *want* to study and learn.
- 29% volunteer – 52% *want* to volunteer.

Family members/allies have a slightly different take on what would be a good fit when it comes to daily activity for the ASD adult they describe, with most identifying social recreational activities (79% of 163 respondents), work for money (58%), volunteer work (50%), study/learn (42%) and spend time at home (28%). They provide diverse descriptors of what "good fit" activities could like, including activities that involve other people, a combination of activities, part-time work, recreational activities, skills and coping skills training. Some comments suggest that balance and diversity is important (such as "a bit of each" of the categories suggested, and "part-time" work and study. The need for support for activities of all types is also prominent in family member/ally comments.

Of note, for NVLV ASD adults, the vast majority (87%) of family members/allies say that social recreational activities would be a good fit for a daily activity. Comments from these respondents identify that additional supports and well thought out activities that are simulating, positive and accessible are required.

Most (80%) of ASD adults aged 40+ years say that they want to do more activities and 63% would like to work for money.

What they say: about daily life

"… all of us are existing and we are NOT LIVING we are here at home doing next to absolutely nothing due to different abilities and hurdles and depression and physical limits…"
ASD adult

"A balance of activities is necessary to keep him connected to the community and help him grow into more potential. He is capable of more then he realizes."
Family member/ally

COVID-19 is a major cause of change in daily life for ASD adults

A very large majority of ASD adult respondents (82% of 101 respondents) and family members /allies (85% of 162) identify that COVID-10 has changed their daily activities (in the case of family members/allies, activities of the ASD adult in their care). This is not surprising, given the shut-down of many services in the Ottawa area throughout COVID-19 (and continuing).

Over 75 ASD adults described various ways that COVID-19 has affected their lives and over 130 family member/ally respondents commented on how COVID-19 had impacted the ASD adult they describe. Comments are diverse, and most focus on what is lost/not available and how that impacts ASD adults and families/allies. Public health restrictions required programs of every sort (work, volunteer, social/recreation, school) to close or be to have access drastically limited – as is the case for the wider community.

Survey results show that NVLV ASD adults have been significantly affected by COVID-19: 96% of ASD family members or friends report that daily activities for ASD adults have changed. Respondents' comments highlight the cancelation of day programs and the lack of access to in-person activities. (See *Snapshot #5: Non/Less Verbal ASD adults*, page 45)

Many comments point to the negative impacts of COVID-19, with a few suggesting that the requirement to stay at home is welcome. Others are neutral (such as "went from reporting to an office m-f [Monday to Friday] to working from home full time." Some

What they say: impact of COVID-19

"… living in a rural community knowing no one is really lonely each and every day with cov19 its 1000x worse…"
ASD adult

"Lost my job, lost funding from OW [Ontario Works]. ASD adult

"All programs closed, no more support, no more outings, no more respite, no more social interactions, parent burn/care person out.
Family member/ally

"Staying home so much has caused mental health concerns to become more serious." ASD adult described an increase in stress levels, loss of any contact with others, and impact on mental health of ASD adult and caregivers.

Considerations and Conclusions Related to Theme 2

Theme 2: Many ASD adults want to participate in paid or voluntary work, and/or study and learning opportunities, yet opportunities are limited and come with major challenges.

Findings that align with Theme 2 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

- **A comprehensive network must support better alignment of services to needs and support ASD adults' goals, abilities and interests.** The ASD adult community includes a very wide diversity of abilities, capacities and interests. While the community is diverse, there is a clear and widespread desire by ASD adults to spend time outside the home, and/or to be engaged in work, activities and volunteerism. Any comprehensive network should better connect ASD adults with desired roles outside the home and in activities, employment or volunteerism, studying and learning opportunities. Awareness and education for employers as well as, volunteer and educational/learning organizations is also essential.
- **To reflect the strongly expressed interest in employment and volunteerism, a network should reflect a better understanding of how these activities contribute to both socially valued roles for a population that has been overwhelmingly devalued, and financial autonomy**. Social Role Valorization[11] or comparable foundational principles should be included in the design of a network model. ASD adults sent a strong message that lack of money is a barrier to many aspects of their lives – a network model should include ways of building and supporting financial autonomy for ASD adults. A comprehensive network must align with the need for valued social roles and financial autonomy through a wide array of employment and volunteering supports, such as mentorship, self-employment supports), and education for employers about the benefits of employing people with ASD.
- **The need for and value of "financial autonomy" for ASD adults should be reflected strongly in selection/development of a network model, given the strong message from consultations by ASD adults that lack of money as a barrier to many aspects of their lives.** In the small group consultations and interviews, the limitations of financial supports (ODSP and employment in particular) were repeatedly highlighted as a need and a barrier to many aspects of a better life for ASD adults. Offering supports, services

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[11] Social role valorization (SRV) is defined as the use of culturally valued means to enable, establish, enhance, maintain, and/or defend valued social roles for people at value risk. Wolfensberger W. Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation.* 1985;31:234–238.

and resources to support financial agency of ASD adults in Ottawa will be a critical part of network offerings. This issue should also be further explored in the context of the extent to which ASD adults are involved in important life decisions.

Theme 3: To better support their physical and mental health, above all, ASD adults need professionals across diverse services who understand autism.

Summary of Findings

Physical and mental health are major components of life satisfaction. Survey results indicate that ASD adult respondents have somewhat better physical health than mental health. When asked how they feel about their physical and mental health, ASD adults are much more likely to feel more positive about their physical health (40% of 95 respondents), saying it is good (25%) or excellent (15%).

How ASD adults feel about their physical health (n=95) and mental health (n=100)

	Physical health	Mental health
Excellent	15%	4%
Good	25%	20%
Okay	41%	45%
Not good	14%	23%
Terrible	5%	8%

A smaller proportion is positive about their mental health (24% of 99 respondents), saying it is good (20%) or excellent (4%). Looking at the negative possible responses (not good or terrible), again, 19% chose this response for physical health, and 31% chose a negative choice to describe how they feel about mental health.

Among ASD adults aged 40+ years, about one third (35%) say they feel good (31%) or excellent (4%) about their physical health, while a slightly smaller proportion (31%) feels positive about their mental health – with all of those respondents saying they feel good (31%) and none (0%) saying they feel excellent about their mental health. One third (31%) feels negative about their mental health, with the majority of these saying they feel not good (23%) or terrible (8%) about their mental health. (See *Snapshot #6: ASD Adults Aged 40+ Years*, page 50)

One half of ASD adults say they are physically healthy—and they identify health challenges

With respect to physical health, over one half of ASD adults (54% of 95 respondents) say they are "healthy." At the same time, over one third (39%) say have pain, and/or have trouble moving (37%), and 21% have allergies and/or an illness (11%). Family members/allies paint a different picture, with allergies identified by 40% of 146 respondents, and with pain and mobility

Figure 7: Physical health of ASD adults

	ASD adults (n=95)	Family members/ allies (n=146)
I am healthy	54%	N/A
Have pain	39%	20%
Have trouble moving/mobility	39%	14%
Have allergies	21%	40%
Have an illness	11%	14%
None of above (ASD adults)/ Don't know (family members/allies)	1%	15%

challenges less prominent compared to proportions identified by ASD adult respondents. (See Figure 7)

ASD adults are less likely to say that they are "fine" with respect to mental health is fine, compared to their physical health

With respect to mental health, 25% say they are "fine" (the most health-positive answer from a different pre-set list of possible answers). (See Figure 8)

Moreover, a majority of ASD adults identify negative mental health issues from a pre-set list, with stress/anxiety topping the list (76% of ASD adult respondents chose this), trouble focusing (62%), forgetfulness (53%) and feeling depressed 52%). Almost one half (46%) say they have mood swings, and over one third (37%) have hard to control frustration/anger. (See Figure 8)

Figure 8: Mental health of ASD adults

	ASD adults (n=99)	Family members/ allies (n=158)
I am fine	25%	N/A
Stress/anxiety	76%	94%
Trouble focusing	62%	47%
Forget things	53%	34%
Feel depressed (ASD adults) Sadness/ depression (family members/allies)	52%	58%
Mood swings	46%	51%
I have hard to control frustration/anger	37%	41%
None of above (ASD adults)/ Don't know (family members/ allies)	2%	2%

Responses from family members/allies of ASD adults point to a different mental health profile than that reported by ASD adult respondents. Almost all (94%) family members/allies report that the ASD adult they describe experiences stress and anxiety, as well as sadness or depression (58%), mood swings (51%), trouble focusing (47%), anger management (41%) and forgetfulness (34%). A number of comments suggest that OCD and sleep issues are challenges for some ASD adults.

Family members/allies responses show that most (88%) ASD adults in the NVLV sub-group experience stress and/or anxiety. They also cite mood swings, sadness/depression and anger management. (See *Snapshot #5: Non/less-verbal ASD Adults*, page 45)

Among the sub-group of ASD adults aged 40+ years, almost three quarters (71%) say they feel stress and anxiety, with almost as many (67%) saying they have trouble focusing. Almost one third (29%) say they feel fine about their mental health. (See *Snapshot #6: ASD Adults Aged 40+ Years*, page 50)

Professionals who understand autism is the number one need identified by ASD adults, family members/allies and professionals to enable ASD adults to improve their physical and mental health

Having access to professionals who understand autism is consistently the top-identified need to support ASD adults with physical and mental health, with over two thirds (69%) of ASD adults and over three quarters (77%) of family members/allies pointing to this need. (See Figure 9) The vast majority of professionals (84% of 63 respondents) identify a lack of professionals who understand autism as a barrier to accessing physical and mental health care for ASD adults.

Figure 9: Needed for ASD adults to take better care of their physical and mental health

	Needs to address physical health		**Needs to address mental health**		**Barriers to accessing health services**
	ASD adults (n=59)	**Family/ allies (n= 155)**	**ASD adults (n=68)**	**Family members/ allies (n=154)**	**Professionals (n=63)**
Professionals who understand autism	69%	79%	82%	77%	84%
Money for health services	56%	23%	60%	29%	73%
Support with appointments	36%	46%	40%	37%	68%
Transportation to health services	36%	23%	37%	24%	62%
Sensory-friendly medical offices	32%	26%	35%	25%	70%
None of above/don't know	15%	8%	7%	10%	0%

ASD adults also identify money for services as something they need in order to address their physical health (56%) and mental health (60%). Most (73%) professionals identify money for services as a need for ASD adults to access health/mental health services.

In comparison, over one quarter (29%) of family members/allies identify that money is a barrier to accessing health care services. Participants across the board in consultations and interviews identified financial constraints as a significant barrier to accessing the professional services needed.

Looking at professionals' responses to the question about barriers to accessing physical and mental health services, they consistently identify all barriers on the pre-set list. (See Figure 9)

What they say

ASD adults need money for health services

[Barrier to accessing needed services…] "affordable, available, inclusive therapy" ASD adult

"Money is a HUGE barrier. Therapists who understand autism are primarily accessed through private practice. It's not affordable to those on ODSP."
Family member/ally

[Barrier to accessing needed services…] "psychologists and psychotherapists not being covered under OHIP" Professional

Considerations and Conclusions Related to Theme 3

Theme 3: To better support their physical and mental health, above all, ASD adults need professionals across diverse services who understand autism.

Findings that align with Theme 3 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

- **To improve physical and mental health outcomes for ASD adults, professionals across many disciplines need to have a better understanding of ASD adults and of autism.** Clearly, ASD adults struggle to receive good care from professionals. Essential to any network model selected is a concerted and ongoing information/education agenda for health professionals and service providers, as well as others who become involved in the health and well-being of ASD adults (for example, lawyers.)
- **Specifically, an Ottawa network needs to offer connected interdisciplinary supports, services and resources as well as widespread and consistent education/ information.** Recent research (related to children but it can be assumed to be the same for adults) suggests that care coordination may serve as a tool to help reduce unmet needs.[12] Further research will be useful to ensuring that a network is developed in ways that meet needs and reduce gaps in service. Education and information tools should offer consistent awareness messaging, information packages for mental health/health professionals, learning opportunities for health partners and possibly direct support with appointments for ASD adults.
- **Co-occurring mental health conditions are highly prevalent in the ASD population and mostly significantly higher than in the general population**.[13] Consultation findings show that many ASD adults, and family members/allies, identify that ASD adults experience various and multiple mental health conditions/challenges. Any network model selected or designed needs to include mental health assessment as an important component of care and should be integrated into any supports and services for ASD adults.
- **Promotion of better understanding of autism extends far beyond health partners to the broader community with a goal of contributing to Ottawa becoming an autism-friendly city.** Some cities around the world that are considered autism-friendly focused efforts on raising awareness, removing main barriers to inclusion and created autism-friendly spaces for people with ASD. Examples of Autism friendly cities include Phoenix, Arizona, Clonakilty (Ireland) and Port-aux-Basque, Newfoundland.

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[12] Berg, K. L., Shiu, C. S., Feinstein, R. T., Msall, M. E., & Acharya, K. (2018). Adverse Childhood Experiences Are Associated with Unmet Healthcare Needs among Children with Autism Spectrum Disorder. *The Journal of pediatrics*, *202*, 258-264.

[13] https://www.eenet.ca/resource/research-snapshot-more-people-autism-have-co-occurring-mental-illness-general-population

Theme 4: ASD adults need help, support and tools to be more involved in important life decisions. Caregivers agree.

Summary of Findings

ASD adults feel good about their role in important decisions

As set out in *Snapshot #4: Decision making* (page 43), one third of ASD adults (64% of 97 respondents) say they feel good (41%) or excellent (23%) about the power they have to make their own decisions, with 10% feeling not good, and none saying they feel terrible.

Among the sub-group of ASD adults aged 40+ years, three quarters (76%) say they make all the important decisions in their life – and most (69%) feel good (43%) or excellent (27%) about their power to do so. (See *Snapshot #6: ASD Adults Aged 40+ Years*, page 50)

Family members/allies of the NVLV group identify that three quarters (74%) of ASD adults do not make important decisions about their life.

ASD adults, family members/allies and professionals agree on prime needs and barriers to better decision making

At the same time, findings from across all sources point to what ASD adults, family members/allies and professionals believe is needed to support greater involvement in important decisions in ASD adults' lives.

Across the three groups of survey respondents, all identify help solving problems is the top need for ASD adults to make better decisions. (See Figure 10) Overall, all three groups agree on the order of needs. While access to legal advice is the identified as less important than other pre-listed needs/barriers, during small group consultations and, to a lesser extent, in individual interviews, legal support was raised as very important.

Of note, almost one in five of (18%) of ASD adult respondents and 10% of family members/allies chose "none of the above" as a response to what is needed in this arena. (See Figure 10). They listed other needs, including: non-biased help (i.e., not from family), more financial support for housing (ODSP is inadequate),, transportation more training for support person on how to involve ASD person in important decisions. Several family member/ally respondents note (in supplementary comments) that the ASD adult they respond about does not have the capacity to make major decisions (severity of disabilities, that the person is "low functioning," lacks a "realistic understanding of how the real world works").

What they say
Needed for better decision making

"…I need acknowledgment of my autonomy and support for my decisions…" ASD adult

"Most of the difficulty I encounter in making good decisions is bound up in mental health, rather than specific to decision-making, difficulty being taken seriously…" ASD adult

"Staff make decisions for them even though he could make decisions about what to eat/snack on/do next, could be make by him. They teach him learned helplessness.
Family member/ally

Family members/allies of NVLV ASD adults identify most frequently barriers to making decisions as: tools to communicate decisions (52%), support to make decisions (44%) and help solving problems (41%).

Figure 10: Needed for ASD Adults to make better decisions/ barriers to decision making

	ASD adults (needs) (n=96)	Family members/allies (needs) (n= 156)	Professionals (barriers) (n=65)
Help solving problems	61%	65%	85%
Support to make own decisions	51%	58%	86%
Tools to communicate decisions	44%	47%	82%
Access to legal advice	28%	19%	42%
Other	N/A	N/A	5%
None of above	18%	10%	2%

In addition to their strong support for the pre-set list of needs (see Figure 10), professionals respondents offer a range of other supports they see as needed for ASD adults making important decisions, including:

- a consistent resource to check in with for guidance on diverse types of decisions
- education and tools aligned with learning styles
- skill building (self-advocacy, assertiveness, financial literacy, organization)
- access to mentors other than parents support to caregivers on how to encourage their ASD adult's autonomy and independence.

They also identified some barriers, including: lack of cognitive capacity of some ASD adults to make important decisions, risk aversion by others, lack of housing, and opportunity for decision making.

Considerations and Conclusions Related to Theme 4

Theme 4: ASD adults need help, support and tools to be more involved in important life decisions.

Findings that align with Theme 4 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

- **Having a say in important decisions contributes to quality of life[14] – more work is needed to understand how and to what extent ASD adults are involved in making important decisions in their lives.** Research indicates that people with ASD frequently experience a number of difficulties in decision-making, including mental "freezing,"

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[14] Brown, Ivan & Brown, Roy. (2009). Choice as an Aspect of Quality of Life for People With Intellectual Disabilities. Journal of Policy and Practice in Intellectual Disabilities. 6. 11 - 18. 10.1111/j.1741-1130.2008.00198.x.

anxiety, exhaustion, slowness in reaching a decision, a tendency to collect too much information, and impaired flexibility, such as making decisions on the basis of previous choices.[15] Further investigation is needed to tease out more fully what is meant by "important" decisions. Moreover, ASD adults need support to be strong self-advocates in important life decisions.

- **Any network selected or designed must recognize and reflect that no matter what the executive function or diversity of barriers, decision making is a critical element to autonomy and to honouring the choices of people.** For this reason, supports for ASD adults to make their own decisions is vital, as are tools to help communicate those decisions. As noted above, this is an important area for future work and understanding.
- **Decision making and supports to strengthen the role of ASD adults in important decisions must be central as a value and/or guiding principle in any newly selected or designed network for ASD adults in Ottawa, if it is to be comprehensive.**
- **Types of decisions to be made evolve over adulthood and become more complex.** A new network must consider that ASD adults – as they and their family members age – may well be the caregiver to the caregiver (for example, caring for elderly parents). Family members and allies identified in the consultations the importance of decision making in considerations of care that may be bidirectional and complex. ASD adults may receive family support, but they may also, especially as they age, provide support to their family members.

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[15] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6795545/#R39

Theme 5: For a secure future, ASD adults need financial resources, a personal support network, a plan and a home – fear about the future is a major source of emotional pain for family members/allies.

Summary of Findings

Most people, whether ASD adults, caregivers, professionals agree that a secure future is vital for ASD adults – and that the future for many does not look secure for myriad reasons.

Most ASD adults do not feel good about their future

When asked how they feel about their future, the biggest proportion (38%) of ASD adults say they feel not good (28%) or terrible (10%). A smaller proportion (30%) say they feel good (24%) or excellent (6%).

How ASD adults feel about their future (n=96)	
Excellent	6%
Good	24%
Okay	31%
Not good	28%
Terrible	10%

Older ASD adults (aged 40+ years) are more likely than all ASD adults to see the future as negative. About one half (48%) say they feel not good (32%) or terrible (16%) about their future, with none (0%) saying they feel excellent about it and 20% saying they feel good. (See *Snapshot #6: ASD Adults Aged 40+ Years*, page 50)

ASD adults, family members/allies and professionals agree on key needs for a secure future

Almost three quarters (71%) of ASD adults identify that there are one or more barriers keeping them from seeing the future as secure.

From a pre-set list, ASD adults identify top needs for a secure future as: enough money (83%), friends/close relationships (78%), a plan (67%) and a home of their own (52%). (See Figure 11)

Figure 11: Needed for ASD Adults to have a secure future/barriers to a secure future

	ASD adults (needs) (n=82)	Family member/ allies (barriers) (n= 159)	Professionals (barriers) (n=65)
Enough money	83%	72%	85%
Friends/close relationships	78%	78%	86%
A plan	67%	72%	85%
Own home	52%	52%	47%
None of above/don't know/other	2%	3%	9%

Both family member/ally and professional survey respondents also identify these needs as important. (See Figure 11) Family members/allies of NVLV ASD adults noted similar top needs: enough money (76%), a plan (76%), friends/close relationships (74%), and a home of their own (57%).

Other needs identified by ASD adults…

Including more nuanced expressions of the key needs identified in Figure 11, other needs ASD adults identify include:

- a stable job
- freedom of having own home
- skills such as cooking, budgeting and driving
- being open to help/less perfectionism
- trust
- help with anxiety
- help with an illness
- feeling validated

What they say

Needed for a secure future

"I need autistic-led efforts to dismantle systemic ableism in all spheres of society." ASD adult

"I worry that my mental state will deteriorate as I age and I will lose my job." ASD adult

"The major barrier is uncertainty. You can make all the plans you want, but you have no idea if they will pan out." Family member/ally

Other needs identified by family members/allies of ASD adults…

Among other needs/barriers offered by family members/allies – the group who is primarily responsible for the future of their ASD adult – some key themes emerge. These include needs for:

- **ongoing care and support**, including when parents are no longer alive: circle/network of people to provide lifelong oversight and care, a support network, an oversight person/network
- **secure employment**
- **supportive home**: a home that is safe and happy, suitable group home (with appropriate supports to meet needs), including shorter wait lists for group homes
- **more certainty**: with respect to housing, plans, employment

While professionals did not offer additional needs or refinements to the pre-listed needs in the survey, during small groups and individual interviews their awareness of the importance of a secure future to ASD adults and, equally, to their caregivers, was clear. In particular, they emphasized the need for a plan that encompasses the core needs of housing (individualized housing plan), financial security, social life and autonomy and education options. They also emphasized the importance of autonomy, the human rights and needs of ASD adults (similar to those of society in general) to accessing their community and all it offers – and access to the supports they need to do so.

Moreover, during small group consultations, the concept of "systems navigators" came up as a possible way role that could better support ASD adults (and family members/allies) to find appropriate services that meet individual needs. In discussions about the usefulness of systems navigators, participants added the caveat that the service gaps need to be filled – otherwise navigation is not useful.

Considerations and Conclusions Related to Theme 5

Theme 5: For a secure future, ASD adults need financial resources, a personal support network, a plan and a home – fear about the future is a major source of emotional pain for family members/allies.

Findings that align with Theme 5 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

- **The need for a secure future is universal and, for ASD adults who are more vulnerable and marginalized than the general population, it is particularly important.** ASD adults and family members/allies identified that a secure future includes financial resource, a personal support network and a home.
- **Behind a secure future is the peace of mind that comes with knowing that the ASD adult, the family members/allies have measures in place to support a safe and secure future.** These include measures that safeguard them from poverty, isolation, loneliness and homelessness when circumstances change along their life course.
- **As they age, ASD adults need access to financial and other resources to provide for a secure future. This is vital for ASD adults with and without family members/allies who advocate for and support them.** For many, such resources are not readily available, even for immediate needs, let alone future needs.
- **Any comprehensive network selected or designed for the Ottawa areas needs to include resources to support future planning.** These likely should include lawyers who understand autism (for retirement and estate planning), facilitators – including systems navigators – who understand autism (for personal support network development), housing providers, financial planning experts, and others – all who have been educated and informed about autism and the diverse needs of families supporting an ASD adult. A network should also include learning or working group opportunities for ASD adults and family members on key topics that are integral to secure futures.
- **A secure and safe future is more likely to arise from a secure and safe present.** The design of a network should reflect the inclusion of security and safety throughout the life of an ASD adult—as a value or guiding principle.

Theme 6: An individualized housing plan is paramount to ASD adults, family members/allies and professionals – for a better life now and in the future. Barriers to housing seem insurmountable and overwhelming.

Summary of Findings

As set out in *Snapshot #1: Living arrangements*, page 38), most ASD adults live with family: one half (49%) of ASD adult respondents, over two thirds (69%) for whom family members/allies responded to the survey, and three quarters (76%) of NVLV ASD adults. The findings point to a lack of autonomy and independence with respect to housing for ASD adults.

When asked how they feel about their home life, over one half (55% of 105 ASD adult respondents) say they feel good (40%) or excellent (15%) about home life.

How ASD adults feel about their home life (n=105)	
Excellent	15%
Good	40%
Okay	36%
Not good	6%
Terrible	3%

"Right" housing is important to ASD adults, family members/allies and professionals – for a better life now and for a future that is safe and secure

At the same time, survey, small group and interview findings point to the need for individualized housing plans as the key to future security. This is especially the case for family members/allies who identified their ASD adult as NVLV.

Figure 12: Home of own as need/barrier

	ASD adults (need)	**Family members/ allies (n=159) (barrier)**	**NVLV ASD adults (n=54) (barrier)**	**Professionals (barrier)**
Home of own (for secure future)	52% (n=82)	57% (barrier)	57% (barrier)	57% (n=65)
Money to live how/ where want (for better home life)	61% (n=69)	42%	33%	72% (n=67)
Housing right for me/them (for better home life)	41% (n=69)	48%	54%	75% (n=67)

For all groups of survey respondents, housing arises as an important need[16] for both the present (as a contributor to better home life) and to feel that their future is more secure. The various respondent groups (ASD adults, family members/allies and professionals) identify more or less frequently needs/barriers related to housing, with emphasis on needs differing somewhat. (see Figure 12) For example, ASD adults identify money to live how/where they want as a need for better home life more

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[16] ASD adults were asked what they need for a better home life and a more secure future. Family members/allies and professionals were asked about barriers to ASD adults having a better home life and a more secure future.

frequently than housing that is right for them. Family members/allies and professionals all identify (57%) that a home of one's own is a barrier to ASD adults having a more secure future. (See Figure 12)

Future security, including safe, supportive, appropriate housing, is a significant issue for family members/allies responding about an ASD adult—and a major source of emotional pain

As noted earlier, three quarters (72%) of family members/allies self-identify as the primary caregiver for the ASD adult they describe in their survey responses. During small group discussions and individual interviews with self-described caregivers, the emotional pain and worry they expressed was palpable.

Many in late mid-life or as seniors worry about what the future holds for their loved ASD child. More than any other issue discussed, the future holds extreme uncertainty for families. The consultants heard time and again that parents want to know that their child will be housed and cared for in ways that are appropriate to their child's needs. Their fears range from worry that their child(ren) will not be loved, that they will not be safe from neglect and/or abuse, that they will lose ground on fronts that they (parents and children) have worked on for years, that their child(ren) will be isolated and lonely, and that they will live in extreme poverty.

What they say

What caregivers say is needed for a secure future

"A place to call home with people he likes and gets along with; knowing he is safe and happy."

Family member/ally

"The major barrier is uncertainty. You can make all the plans you want, but you have no idea if they will pan out. For instance: getting a job."

Family member/ally

"Planning for care after parents can no longer provide it."

Family member/ally

Caregivers need support on numerous fronts

As noted earlier, family members/allies do not feel well-supported, with the average "care score" at 35 out of a possible 100 points (159 respondents).

Figure 13: Needed for family members/allies to feel better supported as a caregiver (n=131)

	Family members/ allies
Access to funding to support caregivers	62%
More community/other resources for caregivers	61%
Information on community/other resources for caregivers	51%
Help managing communication/behaviour issues of ASD adult family member/friend	50%
Better understanding by professionals working with us	50%
Help navigating community/other resources for caregivers	49%
Support for dealing with stress of caregiving	48%
Help with daily care tasks	36%

Choosing from a pre-set list of potential needs which, if met, would enable them to feel better supported as caregivers, family members/ allies who identified as caregivers pointed to the need for resources (financial and others). (See Figure 13)

Of note, when asked to identify other supports they need to feel better supported as a caregiver, many family members/ allies pointed to the needs of the ASD adult they care for – not to their own needs. Specific to their needs as caregivers, needs identified include: respite care, support with housework, money for home care, a network of parents supporting each other, ODSP (to lessen financial burden).

During small group/individual consultations, some parents/caregivers said they were exhausted, frustrated (or beyond frustration). Exhaustion was evident in the voices and demeanor of many caregivers. Others clearly channel their frustration into advocacy, including involvement in various community movements to better meet the needs of the ASD adult community in Ottawa.

For some caregivers, housing is integral to a secure future for the ASD adult they support

Future plans for housing is identified in both family members/ allies survey responses as a barrier to a secure future. Over one half (57% of 159 respondents) identified having a home of their own as a barrier to future security for the ASD adult they describe. A number also listed additional needs related to future housing, including: a place to call home with people he likes and gets along with, a group home with “proper support,” co-housing communities, help to maintain a home (to prevent eviction), RDSP funding made accessible for housing needs, not only for retirement, solutions to transition caregiving in an affordable, caring manner, better group home living, and “real” housing opportunities.

During small group and individual consultations, housing was also part of discussions about the future. Several self-identified parents spoke about the need for/their involvement in shaping appropriate housing

What they say

What caregivers say they need to feel better supported as a caregiver

[With respect to the pre-set list of possible needs of caregivers] “I almost felt like putting none of the above, as they seem like re-arranging the deck chairs on the Titanic. We need solutions for transitioning the caregiving in an affordable and caring fashion..”
Caregiver (family member/ally)

“I need a real plan that can be implemented and sustained.”
Caregiver (family member/ally)

“long term solutions as I'm now a Senior Citizen.” Caregiver (family member/ally

What they say

Hearing the pain of caregivers

“As a person over 60, I am reaching the realization that I will not always be around to look after my son. After so many years of being involved in various grass-roots organizations, I am left feeling discouraged at the prospects of my son ever leaving home. Huge societal changes will have to happen for him to have the opportunity to live on his own, with the necessary supports in place. The situation for people like my son, who cannot live or work independently, but who are gentle and eager to please has no solution at this point..”

Family member/ally

“I am a single parent. The weight of responsibility is heavy. I try to cope day to day and not think about what will happen when I can't manage any more.”
Family member/ally

options for ASD adults – models that have been used/show promise elsewhere to provide individualized housing plans with appropriate and as-needed support.

Professionals support the need for individualized supportive housing and related supports

In response to a question regarding what services are missing for their ASD adult clients, professionals offered a number related to housing, including: transitional housing so ASD adults can learn to live independently/semi-independently, housing and housing support (generally), more housing options, including coop housing, skill-building to support independent living, supportive housing for those who cannot live at home and cannot live independently, assisted living, housing in walkable communities, and support for homeless ASD adults. Some stressed that housing needs, like all needs for ASD adults, will be as diverse as the population and need to accommodate individual needs.

Considerations and Conclusions Related to Theme 6

Findings that align with Theme 6 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

Theme 6: An individualized housing plan is paramount to ASD adults, family members/allies and professionals – for a better life now and in the future. Barriers to housing seem insurmountable and overwhelming.

- **Suitable, stable and affordable housing is a basic human need/right that is key to a secure future for ASD adults – and also is riddled with barriers with long and deep roots.** The barriers are often systemic in that there is little access to affordable housing especially in Ottawa where there are very long waiting lists. Affordability is exacerbated by low social assistance rates (ODSP) that have not kept pace with increases in housing or other costs of living. Societal discrimination, lack of understanding of autism, and otherwise inaccessible workplaces and employers prevent widespread employment that is secure, full-time, or well paid. Housing options through private housing providers are simply not accessible to many ASD adults and families – in particular, those with a lower socio-economic status (compared to the general population).
- **Building community-wide awareness and understanding (in particular among housing providers) of needs of ASD adults should be an ongoing component of any network that is selected or designed.** Increasing community understanding overall will have many positive spin-off benefits for ASD adults, for youth entering adulthood and for the enrichment of Ottawa as a community that supports a diverse set of skills and needs. Widespread community understanding will only increase employment opportunities and housing options for ASD adults.

- **Housing for ASD adults does not have a one-stop solution.** The diversity needs of ASD adults means individualized housing plans are required. While a tool is available (from Developmental Services Ontario) to help build individualized plans, completing it requires considerable work and some/many would require guidance and support to do so. Any model for a network must include supports for individuals and families to easily develop individualized housing plans – and must be closely connected to other housing supports and include a “feedback” loop to increase responsiveness of public supports for housing.

Theme 7: Professionals provide diverse yet inadequate support to ASD adults. Professional mostly serve verbal ASD adults and those with less complex needs.

Summary of Findings

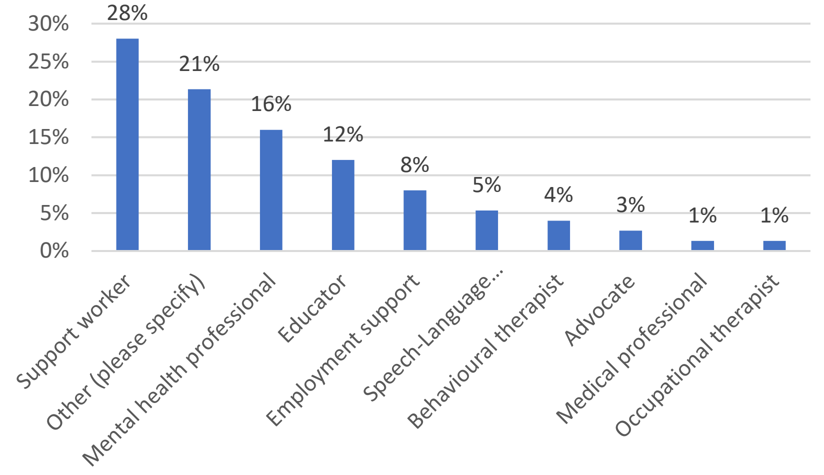
Survey and group/interview questions developed for professionals serving ASD adults were designed to find out how and on what aspects of care professionals work with their ASD adult clients/service population, and to begin to sketch out a picture of the range, scope and nature of services that professionals provide in the Ottawa area. Some survey questions mirror those asked to ASD adults and caregivers to see if there is alignment on some important issues across the community. These findings are summarized below, and include sub-themes that arose during group discussions and individual interviews.

Professionals provide a diverse range of services and supports to ASD adults

Of the 75 professionals who responded to the survey, over one quarter (28%) identify as support workers. Other capacities from a pre-set list include mental health professional (16%), educator (12%), employment support (8%) and a range of others selected by only a few (5% or less) of respondents. (See Figure 14)

Of note, the second most-frequently selected choice is "other" – and responses here include Behaviour Analysist (including Board-Certified Behaviour Analyst (BCBA) and Applied Behaviour Analysis therapist (ABA), as well as coordinator/ manager/ administrator of programs/services, nutritionist, sports therapist and social/life skills coach, and social worker.

Figure 14: In what capacity do you work/have you worked with ASD adults? (n=75)



Most (92%) professionals are currently working with ASD adults, and almost one half (46%) work with up to five (5) ASD adults. About 15% work with each of 11-15 adults (16%), 6-10 adults (15%) and 21+ adults (15%), with 9% working with 16-20 adults.

Professionals work mostly with verbal ASD adults, and those with minor/moderate behavioural challenges and moderate mental health challenges

Overall, 84% of professionals work with adults who are verbal, while 57% work with less verbal adults and 35% with non-verbal adults. The adults they work with are most likely to have behavioural challenges that are minor (67%) or moderate (61%) or with no behavioural challenges (30%). Close to one third (30%) work with adults with severe behavioural challenges.

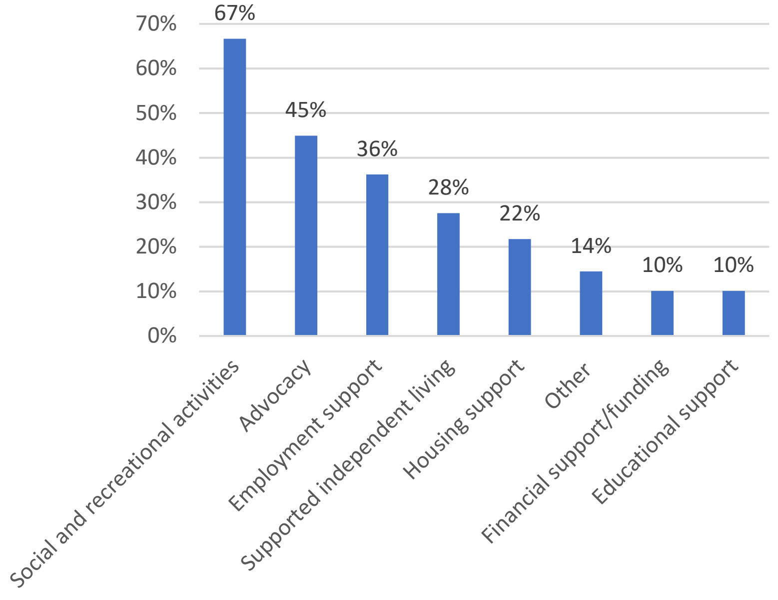
Most of the ASD adults with whom professionals work have mental health challenges, including moderate (80% of adults professionals work with), minor (54%), and severe (29%). About one in five (19%) of professionals say the adults they work with have no mental health challenges.

Professionals are more likely to work in an agency or organization than in other settings

Almost two thirds (59%) of professionals say they do their work with ASD adults in an agency or organization (with another 9% saying they collaborate/contract with an agency to do so). About one third (36%) work in/have a private practice. Other settings (10% of respondents) work in a school setting, group home, hospital program, and research.

In response to the (optional) question about the organizations professionals work with ASD adults, responses overlapped with about one third of those identified by ASD adults as ones they use. These include: March of Dimes, Service, Coordination, ABLE2 Ottawa, Causeway Work Centre, OCAPDD, Christian Horizons, Mainstreet Community Services, Ottawa-Carleton Lifeskills, and The Space. Others mentioned (by more than one respondent) include: Canadian Mental Health Association, and City of Ottawa, as well as a number mentioned by one respondent each.

Figure 15: What support do you/your agency or organization offer? (n=69)



Professionals work at/with agencies more likely to offer social/recreational activities more than other support

One third (67%) of professionals responding to the survey say the agency they work with provides social/recreation activities, with close to one half (45%) providing advocacy and over one third (36%) providing employment support. Notably, about one quarter provide supported independent living (28%) and/or housing support (22%) – both significant needs identified by ASD adults and caregivers. (See Figure 15)

Among the “other” supports identified by professionals, counselling and mental health supports are mentioned frequently, including some specific services such as assessment, psychotherapy, behaviour supports, coaching, daily living skills, social skills, respite, supports to those with concurrent disorders, and system navigation.

With respect to their ASD adult workload, over one third (38% of 68 respondents) say they are “full,” with a waiting list, and about one quarter have a workload that is fairly full (24%) or space for new clients (25%).

Referrals to professionals surveyed come from various sources, including from other professionals (66%), family and friends (60%), direct request from an ASD adult (51%) and from a developmental service coordinator (50%).

What’s working well/meeting needs—professionals’ perspectives

Professionals surveyed offered numerous and varied responses, including general services/supports and some specific programs that are meeting needs, as reflected in a brief summary of what some professional respondents identify as working well (most of the following received one mention each):

- social groups/hubs/meetups/drop-ins
- one-to-one and/or individualized and specialized services/niche groups that meet unique needs of one or a few
- transportation (including Passport) supports
- fee-for-service supports (such as counselling) for families that can afford them
- supports for verbal ASD adults without behavioural challenges

Several professionals responded to “what’s working well” with responses such as “none” or “very few” or “very little” – or “some work well for some but not others.”

What they say

Professionals talk about services

““My impression is that the services that exist are trying their best but there aren't nearly enough of them.”

Professional

[We need] “Behavior consultants that specialize in Autism – less lengthy wait time for a behavior consultant.” Professional

[We are missing] “Mental health services and staffing support resources (shortage of direct support professionals)” Professional

Some of the same services/supports that some professionals identify as working well are also identified by professionals as gaps (see below) – for example, health services, education services, service coordination/system navigation.

What’s missing with respect to services/supports for ASD adults—professionals’ perspectives

Professionals surveyed offered their opinion on what’s missing from the service landscape for the ASD adults they serve. A brief summary highlights some important gaps in services in

Ottawa and other challenges as seen by professionals working with ASD adults. Note that these responses are shown in the order of most frequently to least frequently mentioned:

- housing support, including for coop housing, assisted living, supports for independent and/or semi-independent living
- social and recreational opportunities—including those that are low-key/meet needs of ASD adults, in a supported/facilitated and/or peer-support environment, opportunities to develop social skills
- day programs of all sorts that meet needs and are accessible
- employment/job supports, options, opportunities, aware/supportive employers, job skills training
- funding and resources in general, and for specific supports (housing, employment, mental health, to subsidize activities and one-to-one supports)
- services for ASD adults who are non/less verbal, have more complex needs (mental health, physical health, behavioural challenges) – including for families, in order to better support health needs and reduce ER visits
- transitional services (child/youth to adult), including for independent living, managing money,
- supports to families and for ASD adults living with families, including respite, other supports needed by families
- generally more one-on-one support for supports needed

Most pressing changes needed in Ottawa area to better serve ASD adults—professionals' perspectives

Given their unique position in ASD adults' lives, professionals were asked what they saw as the top one or two most pressing changes needed in Ottawa to better meet the needs of ASD adults. Responses are varied, with some sub-themes evident:

- **more funding/financial resources/resources**—including funding overall, for specific elements of service needs (such as transportation, living, housing, therapies)—as well as for small organizations run by parents to support ASD adults
- **more/better integrated mental health supports for ASD adults and mental health training for professionals**
- **supportive housing/housing options and housing supports** – including for those who need greater support and those who are able to live more independently
- **centralized facility/place/network** – where people can search for/find available services/connect with services, where "bridging" between organizations and families can occur

Other "most pressing needs" identified by professional survey respondents include: day programs (including for high and low functioning ASD adults and/or NVLV ASD adults), more services overall for ASD adults, more access to employment and/or better job opportunities, as well as better/more understanding by society, educators, professionals and respect for and acknowledgement of strengths of ASD individuals. A national strategy that would force provinces to invest in services for ASD adults was also suggested.

Considerations and Conclusions Related to Theme 7

Theme 7: Professionals provide a diverse yet inadequate number and array of supports and services to ASD adults. Professionals mostly serve verbal ASD adults and those with less complex needs.

Findings that align with Theme 7 help to inform the future scope, nature and purpose of a comprehensive network of supports and services for ASD adults in Ottawa. This brief section attempts to look behind the findings to some underlying factors that will need to be addressed in future work to develop such a network, as well as some more practical suggestions for consideration in developing an effective network.

- **The clear misalignment of availability of services and needs for services to support ASD adults points to an overwhelming priority for any comprehensive network to improve alignment. In particular bridging gaps by encouraging and educating professionals across services areas to fill these gaps**.
- **Alignment of public funding with ASD needs to be a priority for any model of comprehensive network of ASD services and supports.** This goes hand in hand with need for better alignment of services with need (above) and calls for the involvement of elected officials at all levels, among others.
- **Any model of a comprehensive network needs to make a bold move to prioritize some key "difficult to address" needs of ASD adults and their families.** These include housing, individual housing plans, employment/volunteer opportunities, concrete and achievable plans for the future, and other components of a satisfying life and a safe and secure future. While professionals agree that social and recreational services are vital to a satisfying life, they do not respond to some underlying gaps that create instability, uncertainty and insecurity in the lives of ASD adults and their families.
- **Supports and services for ASD adults with more complex needs – including mental health and behavioural needs and particular needs of those who are less-verbal/non-verbal – must be addressed more fully in any comprehensive network model selected or designed.**

IV Summary of Considerations for A Comprehensive Network

The community consultation conducted by the Ottawa Adult Autism Initiative (OAAI) endeavored to better understand the ASD adult community in Ottawa – specifically, ASD adults, family members and allies (including those who are primary caregivers) to ASD adults, and professionals who serve the ASD adult community. Consultation input was received from 442 individuals through surveys, multiple small group consultations and individual interviews, and community validation sessions completed in 2020 and early 2021. The consultation has captured an initial community snapshot and greater understanding of the diverse needs and viewpoints of those in and close to the ASD adult community in the Ottawa area.

Findings from survey responses, small group discussions, individual interviews and community validation sessions tell us that the ASD adults in Ottawa have a very diverse profile and equally varied needs. They face many barriers to achieving the lives they want to live. Overall, finding tell us that ASD adults want to be busy outside the home, be healthy both physically and mentally, have close relationships and a secure future. As a group and as individuals, they face numerous and overlapping barriers that systemic/structural barriers, attitudes of society at large and the very organizations and care providers they need, as well as physical barriers.

A maze of inter-related barriers

For **ASD adults**, access to stable financial resources through employment, or through qualifying for disability benefits are simply not an available option to most. These barriers “support” additional barriers to ASD adults meeting other essential needs, such as access to housing, support to live as they wish, better physical and mental health care and being engaged in social and recreational activities they enjoy. Broadly speaking, ASD adults face barriers in a society that is unaccepting of them, with few prospects to freely access opportunities they want and the help they need – in particular with respect to mental health, financial security (including employment) and housing that meets their needs. COVID-19 has exacerbated their challenges by making the world even more inaccessible.

Family members and allies echo the frustrations of the ASD adults in their lives. They often find themselves in the position of bridge between their ASD loved one and the rest of the world. They, too, have severely restricted access to the resources they need for the ASD adult in their life to live as full a life as possible and, importantly, for them to also live a full life. Many family members and allies are exhausted, overwhelmed and extremely worried about the future—especially a future where they are no longer alive to support the ASD adult in their lives. They feel unsupported and unsure of where to turn for help.

Professionals recognize that they have an important contribution to make to the lives of ASD adults by way of enabling and/or providing skill-building, therapies, education, mental health support, social and recreational opportunities, and research, among others. They know that they are a scarce resource and not well-connected to all the needs in the broad landscape of needs of ASD adults and their families/caregivers. They recognize that they have a limited capacity to serve ASD adults who have more complex needs and challenges, including those who are less verbal or non-verbal. They appreciate that many ASD adults face financial barriers that render their services, even at low hourly fees, beyond reach.

Some bright spots on an overall challenging landscape

While the broad picture for ASD adults reflects significant difficulty and, for families, overwhelm and real fear about the future, the engagement from the ASD adults, family members/ allies and professionals in Ottawa highlights the collective vision to do better. Each group has their own needs and contributions – many of which are operating in silos around Ottawa.

It is clear that a comprehensive network to bridge fragmentated services and supports, to fill gaps in services that don't exist and/or do not meet needs, and to connect people, supports, services and resources are required to achieve that collective vision. This clarity arises directly from the evidence collected. Despite a pandemic which has shut down most of the world, OAAI managed to receive 442 individual inputs into the consultations via the survey, online small group consultation and interviews. This is an amazing feat. The success of this consultation has led to an enormous volume of feedback. The first step is this initial report but there is enough data to inform the development of a city-wide network for the years to come.

Seven Themes and Overall Considerations for Next Steps

Consultation findings point to some clear directions and next steps in the development of a comprehensive network of services and supports for ASD adults in Ottawa, as set out throughout this report. These considerations are set out following a summary of the key themes arising from the consultations.

Theme 1: ASD adults' connection to support agencies/organizations is limited and services available for ASD adults are not aligned to meet individual needs.

Theme 2: Many ASD adults want to participate in paid or voluntary work, and/or study and learning opportunities, yet opportunities are limited and come with major challenges.

Theme 3: To better support their physical and mental health, above all, ASD adults need professionals across diverse services who understand autism.

Theme 4: ASD adults need help, support and tools to be more involved in important life decisions.

Theme 5: For a secure future, ASD adults need financial resources, a personal support network, a plan and a home – fear about the future is a major source of emotional pain for family members/allies.

Theme 6: An individualized housing plan is paramount to ASD adults, family members/allies and professionals – for a better life now and in the future. Barriers to housing seem insurmountable and overwhelming.

Theme 7: Professionals provide a diverse yet inadequate number and array of supports and services to ASD adults. Professionals mostly serve verbal ASD adults and those with less complex needs.

Services, alignment of services with needs, navigation

- **Streamlined access** to services and more **flexible eligibility criteria** to better reflect the needs, priorities and capacities of ASD adults. This will require collaborating with others to advocate for funding to **align with needs**, and for encouraging and educating professionals across service areas to **fill gaps and evolve services** to meet needs. Collaborators need to include established organizations to provide capacity and governance, advice and connections (for example, Autism Ontario).
- Tools for **system-wide navigation** of services and supports that enable easy, transparent and faster access to services and supports.
- Supports and services that **align with the specific needs of non-verbal/less-verbal ASD adults and older ASD adults**, and further efforts to **understand the priorities of ASD adults with complex needs** (including those with dual/multiple diagnoses).
- Mechanisms to **identify and deconstruct systemic and other barriers** to employment and financial autonomy for ASD adults.
- Better information on the **needs and priorities of** ASD adults under-represented in consultations: **Francophones, LGBTQA2S+, rural dwellers, Indigenous people, newcomers, visible minorities**.

Awareness and knowledge

- A strategic plan to improve community and funder understanding of how employment/volunteerism contributes to both **socially valued roles** for ASD adults, and to **financial autonomy**.
- A dedicated **information/education agenda for health professionals and other professionals** involved in the health and well-being of ASD adults (e.g., lawyers, financial advisors) so they better meet the needs of ASD adults.
- A strategic communication/information plan to **promote better understanding of autism across the community** to contribute to **Ottawa becoming an autism-friendly city**.

Support a secure future for ASD adults by creating a secure present

- Supports and tools for **ASD adults to play a strong role in making and communicating important life decisions**, in recognition that decision making is critical to autonomy. This calls for tailored approaches to address complex and evolving needs of non-verbal/less verbal and older ASD adults.
- That suitable, stable, affordable **housing is a right** and essential to the future security of ASD adults. This calls for building awareness/ understanding among housing providers and funders of the importance and **value of supporting housing options** for ASD adults. It also calls for better tools to support ASD adults and their family members/allies to easily develop **individualized housing plans**.

Appendix A

Snapshots: A closer look at six key issues and groups[17]

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[17] Note that some sub-groups of survey respondents that might have been explored more fully in a "snapshot" were too small to allow for a separate analysis – and still maintain confidentiality. These include ASD adults who identify as LGBTQA2S+ (23% of 107 respondents) visible minority (12%), Francophone (10%), rural dwellers (7%) newcomers (3%) and Indigenous (3%).

Snapshot #1: Living arrangements and home life

Among ASD adult respondents, one half (49%) of ASD adults live with their family, while one quarter (25%) live alone. The remainder live with a partner/spouse (15%), with friends/roommates (7%). Only 1% of ASD adults say they live in a group home. Answers from family member/ally respondents to the same question differ, with results pointing to ASD adults they responded about living less independently (e.g., 17% live alone, compared to 26% of ASD adults reporting themselves).

How ASD adults feel about their home life (n=105)	
Excellent	15%
Good	40%
Okay	36%
Not good	6%
Terrible	3%

Over one half of ASD adult respondents (55% of 105 respondents) say their home life is good (40%) or excellent (15%), with a small proportion say their home life is not good (6%) or is terrible (3%). (See Figure 16)

Figure 16: Where ASD adults live	ASD adults (n=106)	Family members/ allies (n= 162)
With family	49%	69%
Alone	25%	17%
With a partner/spouse	15%	2%
With friends/roommates	7%	3%
In a group home	1%	4%
None of the above/other	3%	5%

One half of ASD adults (49% of 106) say there is something stopping them from having a better home life – with one third saying there is not anything in the way. ASD adults are more likely to identify needing money to live how where they want to (61%) compared to 42% of family member/ally respondents, and are more aligned on other needs, such as help to manage their home (52% compared to 50%), help getting along with others (41% compared to 34%) (See Figure 17)

Figure 17: Needed for ASD adults to have a better home life	ASD adults (n=69)	Family members/ allies (n= 159)
Money to live how/where I (they) want	61%	42%
Help to manage home	52%	50%
Help getting along with others	41%	34%
Housing right for me (them)	41%	48%
Transportation	33%	26%
More privacy at home	32%	N/A
Help with anxiety about moving	25%	35%
None of above/other	6%	8%

Snapshot #2: Physical health

How ASD adults feel about their physical health (n=95)	
Excellent	15%
Good	25%
Okay	41%
Not good	14%
Terrible	5%

When asked about their physical health, over one half (54% of 95 respondents) of ASD adults say they are healthy. At the same time, over one third (39%) say have pain and/or trouble moving, and 21% have allergies and/or an illness (11%). Nevertheless, 40% of 95 ASD adult respondents say they feel good (25%) or excellent (15%) about their health, while 22% say they feel not good (14%) or terrible (5%). Another 41% say their health is okay.

Family members/allies were asked about specific health challenges the ASD adults they describe experience, and their responses differ somewhat than responses from ASD adults. Specifically, with respect to the ASD adult they describe, family members/allies say that:

- 40% have allergies
- 20% have pain
- 14% have mobility challenges
- 14% have an illness

It is noteworthy that far more family member/ally respondents identify allergies (40% compared to 21% of ASD adults reporting), and family members/allies are much less likely to identify pain as a challenge (20% of family members/allies compared to 39% of ASD adults).

Professionals who understand autism are essential to support the ASD adult community

One half (48% of 96 respondents) of ASD adults say that something prevents them from looking after their health, 38% say nothing is in the way, and 15% don't know if there is a barrier.

Figure 18: Needed for ASD adults to take better care of their physical health	ASD adults (n=59)	Family members/ allies (n= 155)
Professionals who understand autism	69%	79%
Money for health services	56%	23%
Support with appointments	36%	46%
Transportation to health services	36%	23%
Sensory-friendly medical offices	32%	26%
None of above/don't know	15%	8%

When asked what they need to take better care of themselves, over two thirds (69% of 59 respondents) identified professionals who understand autism. Other top barriers they identified (from a list) including money for health services (56%), support with appointments (36%) and transportation to health services (36%), as well as sensory-friendly medical offices (32%). (See Figure 18) Other barriers they identified (not from a list) include: ability to overcome anxiety, to be “comfortable in my own skin,” childcare, a diagnosis, specific health professionals, motivation, reliable transportation.

Family member/ally survey-takers also identify that professionals who understand autism is clearly a significant barrier, with 79% putting it at the top of the list of barriers to the ASD adult they describe being able to access medical care. Another top barrier identified by family members/allies is support with appointments (46%). Money for health services (23%) is seen as less important than it is for ASD adults (56%). Other barriers noted by both ASD adults and family members/allies include: ability to overcome anxiety and depression, a diagnosis, a rheumatologist to help deal with lupus, legal help (with school-related human rights issue), clarity regarding the boundaries of therapeutic relationships, professionals’ and clients’ expectations, help with motivation, help with chronic pain, access to professionals outside Canada, a good GP, a psychiatrist, help with anxiety, support to express self at appointments.

Snapshot #3: Mental health

When it comes to the mental health of ASD adults, both ASD adults, family allies/allies and professionals who responded to the survey, took part in small group consultations and participated in one-to-one interviews had a lot to say.

Almost one third of ASD adults are unhappy with their mental health

One quarter (24% of 100 respondents) of ASD adults surveyed say their mental health is good (20%) or excellent (4%), and almost one third (31%) say it is not good (23%) or terrible (8%).

How ASD adults feel about their mental health (n=99)	
Excellent	4%
Good	20%
Okay	45%
Not good	23%
Terrible	8%

For both ASD adults and family member/ally survey respondents, anxiety and stress is identified as the top mental health challenge (76% of ASD adults and 94% of family members/allies). ASD adults also prioritize trouble focusing, forgetfulness and feeling depressed (over 50% identify each of these). Family members/allies are slightly more likely to identify feeling depressed/sad and mood swings as important challenges (over 50% identify each of these). (See Figure 19)

Figure 19: Mental health challenges faced by ASD Adults	**ASD adults (n=99)**	**Family members/ allies (n= 158)**
Anxiety and stress	76%	94%
Trouble focusing	62%	47%
Forget things	53%	34%
Feel depressed (or sad)	52%	58%
Have mood swings (happy/sad)	46%	51%
Hard to control frustration/anger	37%	41%
I am fine	25%	N/A
Don’t know	N/A	8%

Professionals who understand autism tops the list of what ASD adults and family members/allies see is needed to improve mental health

Figure 20: Needed for ASD Adults to have better mental health	ASD adults (n=68)	Family members/ allies (n= 154)
Professionals who understand autism	82%	77%
Money for health services	60%	29%
Support with appointments	40%	37%
Transportation to health services	37%	24%
Sensory-friendly medical offices	35%	25%
None of above/don't know	7%	10%

In keeping with this finding, one half of ASD adults (49% of 100 respondents) say there is one or more barriers to them taking care of their mental health, with one third (30%) saying there is not a barrier and 21% are unsure.

When asked to identify barriers from a pre-set list, both ASD adults and family members/allies point clearly to a significant need to improve mental health: professionals who understand autism. As with barriers to physical health, it is the top barrier identified (from a pre-set list). The next most prevalent needs identified by ASD adults themselves are money for health services (60% identified this as a barrier compared to 29% of family member/ally respondents), support with appointments (40% compared to 37% of family members/allies), and transportation to health services (37% compared to 24% of family members/allies). (See Figure 20)

As is the case with physical health, family members/allies are far less likely to see money for health services as a barrier. Other barriers noted by both ASD adults and family members/allies include: getting beyond COVID, legal services, a "whole body, whole mind" approach to health care, health insurance, therapist, ways to meet other high functioning individuals (such as through Zoom), professionals who "actually can understand my issues and not just pass me to someone else," safe and clean housing, financial support for psychologist fees.

Snapshot #4: Decision Making

How ASD adults feel about their power to make important decisions (n=97)	
Excellent	23%
Good	41%
Okay	26%
Not good	10%
Terrible	0%

Having a significant role in important life decisions can contribute to overall satisfaction with life. Two-thirds of ASD adults (64% of 97 respondents) say they feel good (41%) or excellent (23%) about the power they have to make their own decisions.

Most ASD adults say they make important decisions

A closer look at the extent to which ASD adults make important decisions shows that the vast majority (91%) say they make all (52%) or some (39%) of such decisions. When family member/ally respondents answer the same question about the ASD adult they care for, the picture is significantly different: about one half (52% of 159 respondents) of family members/allies say their ASD adult makes all (17%) or some (35%) of these decisions. (See Figure 21)

Help solving problems is most needed to support better decision making

For both ASD adults and family member/ally survey respondents, help solving problems is identified as the top need to support ASD adults making better decisions, with 61% of ASD adults and 65% of family/allies putting it at the top of a pre-set list. Other needs from a pre-set list are identified by both ASD adults and family/allies in the same order of prevalence, with support to make own decisions, identified by over one half of ASD adults (51%) and family/allies (58%). Tools to communicate and access to legal advice feature less prominently. (See Figure 22)

Figure 21: Do ASD adults make important decisions about their life?	**ASD adults (n=97)**	**Family/allies (n= 159)**
Yes – all	52%	17%
Yes – some	39%	35%
No	7%	40%
Not sure	2%	1%

One in five (18%) of ASD adults and one in 10 (10%) of family member/ally respondents said that "none" of the pre-set answers captured their needs and provided a wide range of other needs. They include: acknowledgement of autonomy, fewer decisions to make, someone to bounce ideas off, relationship between mental health and decision making, regular appointments with psychologist, non-biased help (non-family), counseling regarding retirement and long-term care, better financial support to live decently/pay bills. Family/allies identify others, including: financial advice, support for hard conversations about big decisions, ASD ability to understand change/impact of big decisions, willingness of ASD adult to accept help, inability to communicate/understand, training for support people, provision of "too much assistance" by caring people and, similarly, staff making decisions that ASD adult could well make themselves.

Figure 22: Needed for ASD Adults to make better decisions	**ASD adults (n=96)**	**Family/allies (n= 156)**
Help solving problems	61%	65%
Support to make own decisions	51%	58%
Tools to communicate decisions	44%	47%
Access to legal advice	28%	19%
None of above	18%	10%

Snapshot #5: Non/Low-Verbal ASD Adults (as described by family/allies)

As noted earlier, 66% of family member/allies say that ASD adults they describe are able to talk a lot, with 21% able to talk a little and 12% don't talk. This snapshot provides highlights of various findings specifically for non-verbal/low-verbal (NVLV) ASD adults, as per family/allies providing responses about ASD adults.

Family/allies completed a separate survey about (not for) ASD adults. This snapshot provides highlights of those respondents who identify their ASD adult as NVLV. (See sidebar for information about this group.)

About family/allies for NVLV ASD adults

- 72% are the primary caregiver for the ASD adult they are responding about
- As a group, these family members/allies are not feeling well supported, with their rating of care they receive as 31 on a scale of 1-100, with 1 being non-existent, and 100 being excellent
- Family members/allies have many unmet needs to feel better supported, including the following supports for those who identify as caregivers:

More community/other resources	75%
Funding for caregiver support	73%
Help to manage behaviour/ communication of ASD adult	64%
Information on resources available	59%
Support with caregiver stress	57%
Help navigating resources	55%
Better understanding by professionals	52%
Help with daily tasks	52%

A majority of non/low-verbal adults can talk a bit

About two thirds (66% of 55 respondents) of this group are low-verbal ("able to talk a little") and the remaining one third (35%) are non-verbal ("they don't talk"). Other means of communication (from a pre-set list of responses) include: typing (46%); writing (32%); sign language (30%); pointing to pictures/words (30%); and drawing (23%). Other means of communication offered by respondents include using of body language, gestures and pointing, gestures and sounds, action (getting own things, goes to/brings), aggression.

Other highlights include:

- Over one half 53% (of 57) are aged 18-24 years, another 42% are aged 25-39 years. Only 4% are aged 40-59 and 2% are 60+ years.
- The vast majority (93% of 57) were diagnosed with ASD by a doctor as a child.

A majority of non/low-verbal ASD adults are connected to ASD-supportive agencies

Over two thirds (67% of 57) are connected to an agency or organization that supports people on the autism spectrum. From a pre-set list of organizations that provide supports to ASD adults, only two are used by one third or more of non/low verbal adults -- March of Dimes (47%) and Service Coordination (35%). Others are used by a much smaller proportion of this population. (See Figure 23) In addition, respondents added other agencies used including only two used by three individuals (Being Studio and Valor and Solutions – 3 respondents each).

Figure 23: Agencies/organizations connected to (n=57)	**#**	**%**
March of Dimes	27	47%
Service Coordination	20	35%
Citizen Advocacy of Ottawa	8	14%
Christian Horizons	6	11%
WAVE (Dovercourt Community Centre)	5	9%
Main Street Community Services	3	5%
Y's Owl Maclure Co-operative Centre	2	4%
LiveWorkPlay	2	4%
Algonquin College	2	4%
Ottawa-Carleton Association for Persons with Developmental Disabilities (OCAPDD)	2	4%
Ottawa Independent Living Resource Centre	2	4%
Ottawa Foyers Partage	1	2%
Ottawa Rotary Home	1	2%
Tamir Foundation	1	2%
Total Communication Environment	1	2%
Spectrum Insights	0	--
Ottawa-Carleton Lifeskills	0	--
Causeway Work Centre	0	--
The Space	0	--
L'Arche Ottawa	0	--

With respect to the type(s) of service received, two thirds (62% of 42) receive financial support/funding, with one half (48%) receiving social and recreational supports. A much smaller proportion receives other supports: advocacy (21%), housing (21%), employment support (14%), supported independent living (10%) and educational support (10%). For the 12% who receive "none of the above" supports, the most frequently mentioned response (3 respondents) is "day program."

Most low/non-verbal ASD adults stay home most of the day

Three quarters (76% of 55 individuals) spend most of their days at home, with about one third (36%) going to a day program, and 15% working for money and/or studying/learning. Just 7% do volunteer work. A few others identified additional ways of spending the day; the most frequently mentioned is being hospitalized (3 individuals).

Non/low-verbal adults' activities are overwhelmingly impacted by COVID-19

Almost all (96% of 54 individuals) have had activities change due to COVID-19, with only 2% not impacted. Reasons include: programs cancelled, fear/anxiety, supports (volunteers, workers) not available.

Low/non-verbal ASD adults face multiple barriers to doing more activities

Selected from a pre-set list of potential barriers, family/allies identified numerous barriers to the ASD adult they care for doing more during their days, with six (6) barriers selected by almost one half or more of respondents. The most frequently identified barrier is help/support do the activities they want (77% of 57 individuals). Other pre-set barriers are listed in Figure 24.

Figure 24: Barriers non/less-verbal ASD adults doing more/different activities in daily life (n=57)	
Support to do desired activity	77%
Help to be less anxious	56%
Skills needed for desired activity	56%
Activity locations not too crowded	56%
Activity locations not too loud	51%
Transportation	46%
Money for fees/equipment	39%
Don't know	4%

In addition, respondents identified other barriers, including: availability of suitable activities, systemic barriers, behaviour issues, as well as supported protected environment, expectation of ability, communication support, and visual teaching medium.

Most non/low-verbal adults live with family

A full three quarters (76% of 55 individuals) of this sub-group of ASD adults live with family. A much smaller proportion (13%) live in a group home, and 4% live alone. Only 2% live with a spouse/partner and none (0%) live with a friend/roommate). A small proportion have other living arrangements – including in hospital, homeshare, separate space in family accommodation.

Non/low-verbal ASD adults need appropriate housing choice, above all, to improve home life

Over one half (54%) of this sub-group need housing choice that is right for them, while about one third need help to manage home (35%), money to live how/where they want (33%) and help with anxiety about moving (31%). Other pre-set barriers are identified as one quarter of respondents (26% for each of help getting along with people and transportation). Outside of the pre-set choices, respondents offered the need for systemic barriers to be eliminated, for help to trust others, for transitional move from family home, more support at home and other individual needs.

Physical and mental health: non/low-verbal ASD adults face challenges and barriers

Figure 25: Physical health of non/low-verbal ASD adults			
Physical health challenges (n=48)		Barriers to accessing medical care (n= 52)	
Allergies	44%	Professionals who understand autism	85%
Pain	23%	Support with appointments	50%
Illness	17%	Sensory-friendly medial offices	44%
Mobility	13%	Money for transportation to health services	25%
--	--	Money for health services	19%
Don't know	15%	Don't know	6%

Almost one half (44%) of this sub-group report that they experience allergies, with about one quarter having pain. A smaller proportion each experiences illness (17%) and/or mobility challenges. (See Figure 25)

Barriers to accessing medical care are numerous, with professionals who understand autism identified by most (87%) of respondents from a list of pre-set barriers. One half (50%) of individuals in this sub-group identify the lack of support with appointments as a barriers, while one quarter (25%) identify money for transportation. (See Figure 25)

Figure 26: Mental health of non/low-verbal ASD adults			
Mental health challenges (n=53)		**Barriers to mental health care (n= 53)**	
Stress/anxiety	87%	Professionals who understand autism	85%
Mood swings	68%	Support with appointments	43%
Sadness/depression	57%	Sensory-friendly facilities	43%
Trouble focusing	53%	Money for services	30%
Anger management	40%	Transportation to services	30%
Forgetfulness	25%	--	--
Don’t know	6%	Don’t know	3%

With respect to mental health, stress and/or anxiety tops the list of mental health challenges identified for this group, with the vast majority (88% of 53 respondents) citing it as a challenge for the NVLV ASD adult they describe. Mood swings, sadness/depression and anger management are also cited frequently.

Professionals who understand autism is identified by most (87% of 53 respondents) as a barrier to NVLV adults accessing mental health services, with other pre-set barriers each identified by between one third and one half of respondents. (See Figure 26)

Most family/allies say the ASD adults do not make big decisions about their life

Three quarters (74%) of family members/allies say that the ASD adult they describe does not make important decisions in their life – with only one quarter (25%) saying the make some (19%), most (4%) or all (2%) of these decisions.

Barriers to decision making by NVLV ASD adults include lacking tools to communicate decisions

Figure 27: Barriers to non/low-verbal ASD adults making important decisions/more decisions	Family members/ allies (n= 54)
Tools to communicate decisions	52%
Support to make own decisions	44%
Help solving problems	41%
Access to legal advice	17%
Not sure	19%

For family member/ally survey respondents, tools to communicate decisions is identified as the top barrier to NVLV ASD adults making important/more decisions, with over one half (52% of 54 respondents) naming this barrier. They also identify barriers of support to make decisions (44%) and help solving problems (41%), with 17% identifying access to legal advice. (See Figure 27) Among other (non-listed) barriers identified are: cognitive/ comprehension ability and/or lack of capacity to understand.

Non/low-verbal ASD adults face multiple, significant barriers to a fulfilling social life with social and personal relationships

Barriers to NVLV ASD adults having a better social life, as selected from a pre-set list by family member/ally survey respondents are: skills to build and/or keep relationships (74%), support with relationships (69%), ways to meet new people (67%) and help with anxiety (59%), among others. (See Figure 28)

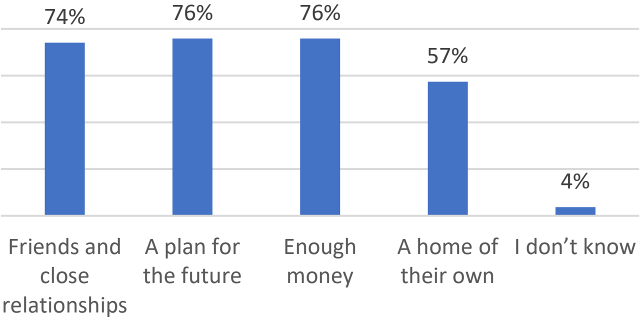
Figure 28: Barriers to non/low-verbal ASD Adults having a fulfilling social life	**Family member/ ally (n= 54)**
Skills to build/keep relationships	74%
Support with relationships	69%
Ways to meet new people	67%
Help with anxiety	59%
Transportation to visit/go out	30%
Money for going out	30%
More privacy at home	9%

Among additional barriers noted by family members/caregivers are lack of interest/focus (on the part of NVLV ASD adult), interest in activities (not people), access to people own age (in a group home), safe places to meet others, and behaviour (unpredictable aggressive outbursts).

Non/low-verbal ASD adults face several significant barriers to a secure future

There are several barriers identified by over three-quarters of family member/ally respondents NVLV ASD adults being able to have a secure future. Three barriers are identified (from a pre-set list) by most respondents: a plan for the future (76%) and enough money (76%), as well as friends and close relationships (74%). Having a home of their own is identified by over one half (57% of respondents). (See Figure 29)

Figure 29: Barriers to your ASD family member/friend having a secure future (n=54)



Respondents also named other barriers, including a caregiver to take over when a parent is no longer able, help to maintain home, too few family members in Canada, a support network/circle of people to provide lifelong care/support, secure funding for housing, societal attitude/knowledge about inclusion, availability/access to day programs of interest/challenge.

Snapshot #6: ASD Adults Aged 40+ Years

A total of 30 respondents to the survey for ASD adults reported that they are aged 40 years or older. This snapshot features highlights of their responses to the survey.

Over one half (57% of 30 respondents) aged 40 years and older responded to the survey using the image-based format (as opposed to the word-based format). Of these, the vast majority (83%) reported that they answered on their own behalf, with 7% answering with help. Another 10% of responses were completed by a caregiver for an ASD adult.

Most (80% of 30 respondents) are in the 40 to 59 year age group, with 20% (6 individuals) aged 60+ years. Close to two thirds (60%) identify as women, 27% as men, and 13% as queergender or non-binary.

Presented with pre-set list of identifiers, 43% (compared to 20% of the total ASD respondents) said that they do not identify with any of the pre-set choices. They offered other identifiers, including: disabled, asexual/demisexual, Aspie, older female. As with the general population of ASD adult respondents, small proportions identify as francophone (17%), a visible minority (7%), living rurally (7%), a newcomer to Canada (3%) – and none identified as Indigenous.

Other highlights include:

- The vast majority (87%) of this sub-group is able to talk a lot, with 10% able to talk a little and 3% not able to talk.
- Almost all say they also type to communicate (93%) and/or write (97%).
- A relatively small proportion (17%) of this group was diagnosed by a doctor as a child (compared to 26% of the total ASD adult respondents). Over one third (37%) of this sub-group report that they are self-diagnosed, and a slightly higher proportion (40%) say they were diagnosed by a doctor as an adult (compared to 27% of the total ASD adult respondents). A small proportion (7%) gave other responses—most often citing informal diagnosis from professionals or others.

A majority of older ASD adults are not connected to ASD-supportive agencies

More than two thirds (70%) of ASD adults aged 40+ years say that they are not connected to an agency or organization that supports people on the autism spectrum, with over one quarter (27% of 30) are connected to such an agency. A small proportion (3%) say they don't know.

From a pre-set list of organizations that provide supports to ASD adults, only one agency (March of Dimes) is used by more than two older ASD adult respondents. Another two (Able 2 of Ottawa and Service Coordination) are each used by two respondents. Several more (9) are used by one – and 14 of 20 (70% of autism-serving agencies) are not used by any respondents in this age group.

Only a small number (8 respondents) identified services received, with only a few reporting that they receive each of social and recreational activities, employment support or none of the pre-set choices. Two or fewer respondents report receiving financial support or supported independent living.

Most older ASD adults stay home most of the day

Two thirds (67% of 30 individuals) spend most of their days at home, with over one third (40%) working for money, one third (33%) studying/learning, and 30% doing volunteer work. Other activities noted include hobbies, being an entrepreneur/self-employed and being retired. While only a small proportion feel "excellent" or "terrible" about how they spend their days (3% each), over one third (30%) feel "good" and about one quarter (23%) feel "not good" about their daytime activities.

How ASD adults aged 40+ years feel about how they spend their days (n=30)	
Excellent	3%
Good	40%
Okay	30%
Not good	23%
Terrible	3%

Older adults' activities are significantly impacted by COVID-19

Over three quarters (79% of 28 individuals) have had activities change due to COVID-19, with 21% not impacted – aligned with responses from the general ASD adult population. Impacts are similar/the same as those identified by the broader ASD adult group – noting that activities have stopped, that they experience isolation (some more than before COVID, others about the same), and for some, layoff from work.

Older ASD adults face multiple barriers to doing more activities

A huge majority (89%) of older ASD adults say there is one or more barriers to them spending time they way they want to (compared to 77% of total ASD adult respondents). Selected from a pre-set list of potential barriers, they identified numerous barriers to the ASD adult they care for doing more during their days. The most frequently identified barrier is lack of money do the activities they want (57% of 30 individuals). Other pre-set barriers identified this sub-group include: lack of help to do the activity (43%), places that are too crowded (40%) or too loud (37%) and lack of help to be less

Figure 30: Needs identified by older ASD adults (40+ years) to enable them to spend time the way they want compared to all ASD adults (all ages)

Older ASD adult respondents (n=30)	**%**	**All ASD adult respondents (n=91)**	**%**
Money to do what I want	57%	Money to do what I want	68%
Help to do desired activity	43%	Help to do desired activity	59%
Places that are not too crowded	40%	Places that are not too crowded	51%
Help to be less anxious	37%	Help to be less anxious	60%
Places that are not too loud	37%	Places that are not too loud	47%
Skills needed for desired activity	33%	Skills needed for desired activity	40%
Transportation	20%	Transportation	48%
None of the above	10%	None of the above	4%

anxious (37%), among others. Compared to the total ASD adult survey population, older ASD adults are less likely than the full ASD adult survey population to identify any of the pre-listed needs. (See Figure 30)

Older adult respondents identified other barriers, including: lack of ability to focus, absence of psychological assessments (provided by Autism Ontario), COVID-19, toxic places (including those where off-gassing occurs), societal biases (of neurotypical people), opportunities to meet other (high functioning) ASD adults/integration with others.

Most older ASD adults live with others (non-family) or alone

Just over one quarter (28% of 29 respondents to this question) of older ASD adults live with family (compared to 49% of all ASD adult respondents). Most live in another arrangement, including alone (34% – compared to 26% of all ASD adults), with a partner or spouse (17% – compared to 16% of all ASD adults) or with friends/roommates (17% – 5% of all ASD adults). None say they live in a group home (compared to 1% of all ASD adult respondents).

About one third (32%) feel good (28%) or excellent (4%) about their home life, with 16% having a negative experience, saying they feel either not good (8%) or terrible (8%). Over one half (52%) say they feel “okay” about their home life. Note that older ASD adults respondents are less likely to feel positive (excellent or good = 32%) about their home life compared to the full ASD adult survey population (55%).

How ASD adults aged 40+ years feel about their home life (n= 28)	
Excellent	4%
Good	28%
Okay	52%
Not good	8%
Terrible	8%

Older ASD adults need money to live how/where they want, above all, to improve home life

Over one half (53%) of this sub-group need money to live how/where they want, while over one third need help to manage home (37%), help getting along with people (32%), housing choice that is right for them (32%). One quarter (26%) need more privacy at home and/or help with anxiety about moving. Transportation is a need for 16% of respondents. Outside of the pre-set choices, respondents offered the need for relationship counselling, meeting others who are high functioning, help getting organized.

Physical and mental health of older ASD adults – many challenges and barriers

Almost one half (46%) of this sub-group experiences allergies, with slightly smaller proportions saying they are healthy (42%), experience pain (42%) or an illness (38%). A smaller proportion experiences mobility challenges (19%). (See Figure 31)

Needs identified by this sub-group of older ASD adults in order to be able to take better care of their physical health are professionals who understand autism (60%) and money for health services (50%), sensory friendly medical facilities (25%), along with supports to with appointments and transportation (20% each).

Figure 31: Physical and mental health of older ASD adults (compared to all ASD adult respondents)

Physical health challenges			Mental health challenges		
Challenge	**Older ASD adults (n=26)**	**All ASD adults (n=95)**	**Challenge**	**Older ASD adults (n= 24)**	**All ASD adults (n=99**
Allergies	46%	21%	Stress/ anxiety	71%	76%
Healthy	42%	54%	Trouble focusing	67%	62%
Pain	42%	39%	Forgetfulness	58%	53%
Illness	38%	11%	Feel depressed	58%	52%
Mobility issues	19%	39%	Mood swings	38%	46%
None of above	0%	1%	Am fine	29%	25%
			Anger management	21%	37%
			None of above	4%	2%

With respect to mental health challenges experienced by older ASD adults, stress and/or anxiety tops the list, with close to three quarters (71%) citing it as a challenge. Two thirds (67%) experience trouble focusing, with over one half (58%) experiencing forgetfulness and/or feeling depressed. Over one quarter (29%) say they are fine with respect to mental health.

Almost one third (31% of 26 respondents) of older ASD adults feel good about their mental health – and none (0%) feel excellent. About one third (31%) have a negative view of their mental health, with 23% saying they feel not good about it, and 8% saying they feel terrible.

Older ASD adults need professionals who understand autism and sensory-friendly medical offices more than any other supports to take care of their mental health

Two thirds (65% of 26 older ASD respondents) report that one or more barriers stop them from taking care of their mental health. Professionals who understand a barrier to accessing mental health services and sensory-friendly medical offices are each identified by 80% of 20 respondents for services is identified by 50% of this sub-group, with other pre-set barriers all identified by less than 20% or less of respondents.

How ASD adults aged 40+ years feel about their mental health (n= 26)	
Excellent	0%
Good	31%
Okay	38%
Not good	23%
Terrible	8%

Most older ASD adults say they make all the big decisions about their life

Over three quarters (76% of 25 respondents) in this sub-group say they make all the important decisions in their life. (In comparison, one half (52%) of all ASD adult respondents say they make all important decisions in their life.) Another 12% of older ASD adults say they make some important decisions (compared to 39% of all ASD adults), 8% say they don't make such decisions (7% of all ASD adults), and 4% are unsure (2% of all ASD adults).

Almost three quarters (72% of 25 older ASD adult respondents) say they feel good (44%) or excellent (28%) about the power they have to make decisions, while 12% feel not good and none feel terrible. These proportions paint a slightly more positive picture than for ASD adults of all ages (97 respondents), of whom 64% say they feel good (41%) or excellent (23%) about their power to make decisions, and 10% say they feel not good (10%) or terrible (none).

To support decision making, older adults need help solving problems and tools to communicate decisions

For older respondents, a number of barriers are identified fairly equally by about one third of respondents, with help solving problems at the top of the list (40% of 25 respondents). (See Figure 32) Among other (non-listed) needs identified are: better options/sources of information and support, access to good information, counselling for retirement and long-term care, and time.

Figure 32: Barriers to older ASD Adults making decisions/more decisions (n=25)	
Help solving problems	40%
Tools to communicate decisions	36%
Support to make own decisions	32%
Access to legal advice	32%
Not of above	20%

Older ASD adults face multiple barriers to a fulfilling social life with social and personal relationships

Well over one third (40% of 25 respondents) of older ASD adults express a positive experience of their personal life, saying they are happy (32%) or very happy (8%). Over one quarter (28%) have a negative view – 16% say they are unhappy and 12% say they are very unhappy.

Barriers topping the list (from a pre-set list) to members of this sub-group having a better social life are skills to build and/or keep relationships (81%), ways to meet new people (57%) and support with relationships (52%) topping the list. Among other (not pre-set) barriers, respondents name lack of self-confidence/ self-esteem, living arrangements, missing appropriate social venues.

How ASD adults aged 40+ feel about their personal life (n=25)	
Very happy	8%
Happy	32%
Okay	32%
Unhappy	16%
Very unhappy	12%

Older ASD adults feel less positive than the general ASD adult population about their future

With respect to the future, 20% of 25 older ASD adult respondents say they feel good about it, with none (0%) feeling excellent. This is somewhat lower than for the general ASD adult population surveyed, where 6% feel excellent and 24% feel good. Moreover, almost one half (48%) of older adults feel not good (32%) or terrible (16%) about their future, compared to 38% of the general ASD adult population who feel not good (28%) or terrible (10%).

How ASD adults aged 40+ feel about their future (n=96)	
Excellent	0%
Good	20%
Okay	32%
Not good	32%
Terrible	16%

Of the 23 respondents who identified barriers to a better personal life from a pre-set list, well over two thirds identify needing enough money (70%), friends/close relationships (69%) and well over one half (57%) say they need a plan for the future. (See Figure 32)

Figure 32: Barriers to older ASD Adults having a secure future (n= 23)	
Enough money	70%
A plan for the future	57%
Friends/close relationships	69%
Ways to meet new people	35%
Own home	26%
None of the above	4%

Respondents also named other barriers, including help with an illness, in-home support, better societal understanding of autism and accommodations, a broader circle of support.

Appendix B: Promising Practices in Autism Support and Service Delivery: Scan of Literature

Prepared by: Jihan Abbas, PhD

Introduction

This literature review focuses on autism supports and services, with an emphasis on potential promising practices for delivery of services and supports. Two key aspects that shape the scope of this review include:

- Barriers and unique issues facing those accessing autism services;
- Potential promising practices for service delivery.

As there is a large body of literature that could speak to these issues, a focus has been placed on research and evidence that can be generalized - both in terms of the needs of persons with autism and related stakeholders, and service delivery mechanisms that have been proven as adaptable. On this last point, it is important to identify models that can be duplicated, adapted, combined, and/or transferred in settings with different policy and legislative considerations.

Context: Serving Vulnerable Populations

General Considerations

Persons with autism, their families, support networks, and allied stakeholders have unique needs that oftentimes require comprehensive and holistic support. Yet research indicates that for this population, there are several barriers that can prevent access to needed supports. In this section, we will outline some of these findings from the research as they are helpful in setting the context in which support is required and thus informing service delivery models that meet stated and unmet needs.

Where autism is concerned, we know that many within this community experience unmet needs. One recent piece of research noted an important connection between a child’s unmet health needs and coordination of care, as those with care coordination reported significantly lower levels of unmet health needs.[18] This speaks to the importance of health care service delivery as an important feature in terms of meeting one's needs and preventing gaps in services. The authors of this research suggest care coordination may serve as a tool to help reduce unmet needs.[19] While there is variance in how care coordination is defined in the literature, one study identifies the following five key elements:[20]

1. Numerous participants are typically a part of the care process.
2. Coordination becomes necessary as participants depend on one another to carry out differing aspects of one's care.
3. Each stakeholder in this coordinated process needs to have information and knowledge about their own and others' roles and resources.
4. In order to manage care activities, there is a reliance on the exchange of information.
5. Integration of care is carried out with the goal of facilitating appropriate delivery of services.

These elements are important, and lay a bit of a philosophical foundation in terms of the elements necessary for coordinated systems of services and supports with multiple stakeholders. Given this, where autism and care needs are concerned, it is important to consider how care coordination and delivery can be both improved and maximized to avoid barriers here.

One important consideration in terms of the context of support and care is the family itself, as research reminds us that the family remains an important source of support for persons with autism across their life course.[21] Not only is the family as a site of care important, but there is also a need to better understand how needs change as one ages and encounters different needs. The availability of resources, services and support for individuals with autism and their families are key to better outcomes throughout one's life.[22] We flag this aspect or a few important reasons.

1. Supports and services must be designed to meet the needs of an individual (and their support) as they age;

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[18] Berg, K. L., Shiu, C. S., Feinstein, R. T., Msall, M. E., & Acharya, K. (2018). Adverse Childhood Experiences Are Associated with Unmet Healthcare Needs among Children with Autism Spectrum Disorder. *The Journal of pediatrics*, *202*, 258-264.

[19] Berg, K. L., Shiu, C. S., Feinstein, R. T., Msall, M. E., & Acharya, K. (2018). Adverse Childhood Experiences Are Associated with Unmet Healthcare Needs among Children with Autism Spectrum Disorder. *The Journal of pediatrics*, *202*, 258-264.

[20] McDonald, K. M., Sundaram, V., Bravata, D. M., Lewis, R., Lin, N., Kraft, S. A., ... & Owens, D. K. (2007). Closing the quality gap: a critical analysis of quality improvement strategies (Vol. 7: Care Coordination).

[21] Grossman, B. R., & Magaña, S. (2016). Introduction to the special issue: family support of persons with disabilities across the life course.

[22] Drmic, I. E., Szatmari, P., & Volkmar, F. (2018). Life course health development in autism spectrum disorders. In *Handbook of life course health development* (pp. 237-274). Springer, Cham.

2. In terms of support networks, there are multiple stakeholders who need to be considered including the individual with autism, their family and caregivers, professional and paid supports (e.g. care coordination considerations etc.)

3. Potential tension between stakeholders is real, and service delivery models should not only identify these tensions, but work proactively to craft responses that meet shifting and differing needs.

This context should always inform the way services and supports are both designed and delivered. With respect to services and how these may shift over the life course, it is also important to note tensions between parents wants/needs and their growing child's wants/needs. Indeed, there are noted tensions between people with disabilities and parents where choice, control and advocacy are concerned, particularly as individuals age and seek more autonomy and independence.[23] There are also tensions between individuals with autism and professionals in terms of best practices. We flag this as it must be a consideration in any long-term planning for this group and their needs.

Thus, it is important to note that addressing issues facing families of those with autism can be difficult as needs change and evolve over time and issues remain broad.[24] Here it is also important to consider care and support as bidirectional and complex, as an individual with a disability may receive family support, but they may also, especially as they age, provide support to their families.[25] As such, any model should be mindful of these complex care relationships over the life course and account for how to best support them.

Research also indicates that service disparities that prevent and impede access for some families, specifically, under-resourced families and their access to high-quality services.[26] As an example, families in lower socioeconomic brackets have shared the need for more information about services as well as the number of barriers they feel make meeting their children's needs difficult.[27] Some of these barriers include:[28]

- A lack of access to information;
- Even in cases where information is accessible, needed information changes over the life course;

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[23] Grossman, B. R., & Magaña, S. (2016). Introduction to the special issue: family support of persons with disabilities across the life course.

[24] Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

[25] Grossman, B. R., & Magaña, S. (2016). Introduction to the special issue: family support of persons with disabilities across the life course.

[26] Pickard, K. E., Kilgore, A. N., & Ingersoll, B. R. (2016). Using community partnerships to better understand the barriers to using an evidence-based, parent-mediated intervention for Autism Spectrum Disorder in a Medicaid system. *American journal of community psychology*, *57*(3-4), 391-403.

[27] Pickard, K. E., & Ingersoll, B. R. (2016). Quality versus quantity: The role of socioeconomic status on parent-reported service knowledge, service use, unmet service needs, and barriers to service use. *Autism*, *20*(1), 106-115.

[28] Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

- An abundance of misinformation (especially online);
- A lack of access to coordinated services;
- Successfully navigating the system requires time, patience, knowledge and persistence.

While each aspect of the above listed barriers is important, we should note that again, the theme of coordinated services emerges. As those with autism and their families likely require vastly different services and supports, at different times and including multiple providers, this aspect of coordination remains a key gap and could potentially speak to an aspect that should be integral to any service delivery model.

While many of these barriers are general and may impact many individuals to a certain degree, there are other unique aspects which may impact access to services and support. As an example, when looking at autism services in rural parts of Alberta and BC, the following barriers emerged:[29]

- Insufficient services;
- Limitation of services related to care in rural settings;
- Protective factors within community that confront change efforts.

Additionally, there is a need to better understand the needs of racial and ethnic minority families, and LGBT families, as much of the existing literature fails to work with diverse sample groups.[30]

Thus, in addition to considerations around the needs of multiple stakeholders and changing needs over the life course, there are practical aspects of a families lived experience that shape their experiences with services and supports. All of these aspects speak to unmet needs, and should inform how services are designed and delivered. Some research suggests that while individuals and families need support on an ongoing basis, both the first diagnosis and transition into adulthood are two phases that require the most intensive support.[31] Families also share that the process of finding, understanding, and applying for services remains a difficult and complex process.[32]

Disruptions & Confusion: Ontario

Given the current climate in the province of Ontario, and changes that have been ushered in under a new government with respect to disability supports, we must recognize that in addition

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[29] Young, A., Nicholas, D. B., Chamberlain, S. P., Suapa, N., Gale, N., & Bailey, A. J. (2019). Exploring and building autism service capacity in rural and remote regions: Participatory action research in rural Alberta and British Columbia, Canada. *Autism*, *23*(5), 1143-1151.

[30] Grossman, B. R., & Magaña, S. (2016). Introduction to the special issue: family support of persons with disabilities across the life course.

[31] Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

[32] Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

to the barriers noted in this review, families and individuals remain vulnerable to political changes (at all levels) and how these shape and change disability supports. As an example, persons with disabilities and families in Ontario find themselves reeling with respect to an onslaught of announcements that fundamentally change existing policies and programs. These include:

- Changes to the definition of disability to align with federal programs.[33]
- An announcement of proposed overhaul of autism services, then after public outcry a change in direction and tasking the government autism expert panel with looking into needs-based and sustainable programming.[34]
- Confusion over services as Ontario’s Ministry of Children, Community and Social services seemingly directed service providers to pause their work with new DSO (Direct Service Option) and DFO (Direct Funding Option) in September of 2018.[35]
- As recently as September 2019 one Northern service provider (Sudbury) has announced that due to government changes no therapy can be offered to new families.[36]

Additionally, recent research with families in Ontario found that across all services (diagnosis, therapy, education, and respite) wait times remain too long and/or services remained inefficient and fail to provide the kinds of supports families required.[37] This had a negative impact on outcomes for children with autism, and even through this research sample largely reflected families with higher socioeconomic status, families are facing high levels of stress, and concerns around physical, mental, and emotional health.[38]

We note these shifts and the related disruptions to services and confusion they have caused, as this context certainly creates additional stress for families in Ontario. As well, as illustrated later in this literature review, unmet needs and confusion and stress around services and supports are a serious concern, so these developments add uncertainty to an already complex process (Ontario’s autism support program already had a backlog of 23,000 children waiting to receive support).[39]

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[33] The Canadian Press (2018) Ontario to change definition of disability as part of social assistance reforms. Available at: https://www.thespec.com/news-story/9046089-ontario-to-change-definition-of-disability-as-part-of-social-assistance-reforms/

[34] Nielsen, K. (2019) Ford government backs off changes to autism funding plan. Available at: https://globalnews.ca/news/5697552/ford-government-ontario-autism-program-funding-changes/

[35] Dhanraj, T. (2018) Emails show autism agency told by ministry to pause contact with families. Available at: https://globalnews.ca/news/4993644/government-autism-support-agencies-ontario/

[36] Alphonso, C (2019) Northern Ontario autism-service provider no longer offering therapy to new families, blames Ford government’s cuts. Available at: https://www.theglobeandmail.com/canada/article-northern-ontario-autism-service-provider-no-longer-offering-therapy-to/

[37] McLaughlin, J. & Scheider, M. (2019) autism Services in Ontario: Impacts on Family and Child Well-Being Research Summary.

[38] McLaughlin, J. & Scheider, M. (2019) autism Services in Ontario: Impacts on Family and Child Well-Being Research Summary.

[39] Pin, L. (2019) Their boy has autism. They’re moving to Newfoundland for help. Available at: https://www.theobserver.ca/news/local-news/their-boy-has-autism-theyre-moving-to-newfoundland-for-help

Key Considerations

To review, some of the considerations in terms of the context of autism supports include:
- The need to address multiple stakeholders and coordinate care;
- The need to respond to shifting needs over the life course;
- The need to provide service delivery models that operate effectively and efficiently in specific and changing policy, funding, and legislative frameworks;
- The need to respond to a crisis in services and supports in the province of Ontario.

Potential Best Practices in Service Delivery

While there are a number of models in terms of service delivery, one critical aspect within the literature is that many of these focus on specific points of service (education, health care etc.). While this is reflected in the literature, there is a need to identify and craft holistic best practices that are accessible across one's lifespan and encompass all those areas an individual requires support.

Given this, we focus here on the Hub and Spoke model, the life course health delivery model, as well as the independent living service model. All of these models offer potential aspects that address the gaps noted in this review, all have been proven effective and efficient in various contexts, and all offer aspects that can be adapted to inform best practices in service delivery models. In this section we briefly introduce each of these models and explore key findings in the literature with respect to their application.

Hub and Spoke: Service Delivery Model

While there is no one set definition of hub and spoke models, they represent a variety of service delivery models arranged around clusters, satellites, and networks.[40] In general, when employed by an organization, this model orders service delivery into a network consisting of an anchor, or the hub, comprised of core services with secondary services, the spokes, which consist of additional services, usually more limited in nature, for those who require more intense service support.[41] One key feature seems to be how this model addresses geographic isolation and distance using spokes and satellites to deliver services to individuals. One review of the literature specific to hub and spoke models and intellectual disability, positioned this model as a multidisciplinary approach based on outreach where the 'hub' is situated in a large area and outreach is provided through the 'spokes' which service smaller more isolated areas.[42]

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[40] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[41] Elrod, J. K., & Fortenberry, J. L. (2017). The hub-and-spoke organization design: an avenue for serving patients well. *BMC health services research*, *17*(1), 457.

[42] Giuntoli, G., Newton, B. J., & Fisher, K. R. (2015). Current models of health service delivery for people with intellectual disability: Literature review.

While used for many different reasons, within the literature, the hub and spoke model is often noted in the healthcare setting and in the delivery of services for children and youth.[43] With respect to its use with children and youth, it has been noted that these systems have developed over time and organically in response to the changing needs of users and shifting funding opportunities.[44] This more organic orientation and the shifting funding environment that shapes it, may speak to similarities with respect to serving people with autism and their families.

While specific to the delivery of healthcare, one research study outlines some of the **benefits** of this model, which can include:[45]

- Consistency - in creating a hierarchy with authority that extends outward, this model offers significant control and command, which offers uniformity in services for users;
- Efficiency - through centralization within the hub, duplications of services can be avoided and economies of scale achieved. Some research also indicates a reduction in the cost of care within this service model;
- Quality - because of the nature of this model, there is an ability to pool resources and expertise which can increase quality in services;
- Enhanced Coverage - as the spoke aspect of hub and spoke model requires reduced resources, less investment is typically required as services expand outward;
- Agility - this model can enhance an organization's ability to adapt as things change and evolve. Additionally, in cases where those aspects served by a spoke are in decline, it can be easier to withdraw.

While not specific to those with autism, in an analysis of serving Indigenous and remote people with disabilities, the hub and spoke model, specific to accessing medical services, has been noted as a potentially appropriate way to reach underserved communities (along with the potential for technology-based tools within the assessment phase).[46]

Thus, within this model there are some unique opportunities and benefits in terms of both centralizing services and outreach capacities. Yet, as with anything, there are **risks** that must be assessed, these include:[47]

- Congestion - as user traffic is routed from spokes to the hub, there is the possibility of congestion at the hub. This requires administrative and logistical considerations to plan to mitigate this potential congestion.
- Overextension - if the spokes are situated too far from the hub (geographically), there can be impacts on service delivery that can lead to potential failures.

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[43] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[44] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[45] Elrod, J. K., & Fortenberry, J. L. (2017). The hub-and-spoke organization design: an avenue for serving patients well. *BMC health services research*, *17*(1), 457.

[46] Biddle, N. (2007). *Indigenous Australians and the National Disability* (Vol. 1, No. 914, p. 842). by ANU Press.

[47] Elrod, J. K., & Fortenberry, J. L. (2017). The hub-and-spoke organization design: an avenue for serving patients well. *BMC health services research*, *17*(1), 457.

- Staff satisfaction - as authority runs from the hub outward, there can be a feeling of discontent and/or lack of autonomy for those who provide services from the spokes.
- Transportation - while research here is not specific to those with disabilities, transportation can be a barrier as this form of service delivery, specifically at the spokes, relies on transportation systems. Of note here, is the need to address the systemic barriers facing those with disabilities where transportation is concerned as this can cause significant disruption to service delivery for this population.

Specific to serving populations with intellectual disabilities the following risks have been noted:[48]

- Staff recruitment and retention;
- Lack of access to services for those who reside further from the spokes.

It has been noted that it is difficult to evaluate hub and spoke models as they are complex and thus it can be hard to untangle linkages that lead to success and challenges.[49] Yet evaluations of healthcare indicate the following potential benefits to this model:[50]

- An increase in the number of people accessing and engaging support;
- Ability to get people into treatment quicker;
- More cost-effective model;
- Hub and spoke service provision does appear to have positive outcomes for users.

A clear benefit of this model is the ability to centralize services within a single site while still distributing additional services via secondary sites, which can, when done well, be incredibly effective and efficient.[51]

One aspect of the hub and spoke model which is clear in the literature, is that it is often used to mitigate challenges that occur because of geography. While conceptualized above in ways that are specific to geographic considerations (in terms of the role of each spoke), it is important to also think about how this model can be applied more flexibly and adapted to serve stakeholders who are generally within the same geographic region. This raises an important question: can the hub and spoke model be used in a way where the "spokes" are organized thematically in terms of services rather than geographically? The recent overhaul of McGill universities mental health services, using a hub and spoke system, does indicate that the hub and spoke model can be replicated to serve smaller areas and populations. As an example, to address the mental health crisis among students, McGill is responding with their own hub and spoke model which consists of a wellness service center, clinically trained "wellness advisors" within various departments and across faculties, a one-stop website to get information, tips for managing

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[48] Giuntoli, G., Newton, B. J., & Fisher, K. R. (2015). Current models of health service delivery for people with intellectual disability: Literature review.

[49] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[50] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[51] Elrod, J. K., & Fortenberry, J. L. (2017). The hub-and-spoke organization design: an avenue for serving patients well. *BMC health services research*, *17*(1), 457.

stress and online access to book appointments.[52] In this iteration of hub and spoke, the physical space occupied by the wellness centre will act as the “hub” while wellness advisors will act as the “spokes” to provide service across campus.[53] So it does seem the hub and spoke model can be utilized and organized to provide services and supports in various settings, including ones where distance and geography are not key considerations.

As well, as the hub and spoke model was not originally designed for those with disabilities, there are considerations that must be made to ensure the model can successfully be applied to this population. For this reason, below we will explore both the life course health development model (LCHD) and the Independent Living model (IL) to better understand how they may meet the needs of stakeholders in the context of autism supports in this region (Ottawa-Carleton).

Life Course Health Development Model

The life course health development model is a biopsychosocial model which is interdisciplinary in nature and appreciates the interconnectedness between one’s biological, psychological, and socio-environmental reality over time. As such, it is both holistic and responsive to needs as they change over time. Both of the aspects are assets given the context of noted gaps with respect to autism services and supports. LCHD include the following phases which reflect the lifespan:[54]

1. Generativity - prenatal period
2. Acquisition of health capacity - early childhood and early adulthood
3. Maintenance of health capacity - middle years
4. Managing decline - later years of life

The authors go on to explore how the six core tenants of LCHD may be applied to individuals whose neurodevelopment differs, and suggest there may be transformative potential in this model as it encourages future planning, a continuity of care, and coordination of services and supports. These six core tenets and their related considerations for this population are as follows:[55]

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[52] Farr, M (2019) McGill to overhaul its mental health service model. Available at: https://www.universityaffairs.ca/news/news-article/mcgill-to-overhaul-its-mental-health-service-model/

[53] Farr, M (2019) McGill to overhaul its mental health service model. Available at: https://www.universityaffairs.ca/news/news-article/mcgill-to-overhaul-its-mental-health-service-model/

[54] Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., ... & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental Medicine & Child Neurology*, *59*(5), 470-476.

[55] Palisano, R. J., Di Rezze, B., Stewart, D., Rosenbaum, P. L., Hlyva, O., Freeman, M., ... & Gorter, J. W. (2017). Life course health development of individuals with neurodevelopmental conditions. *Developmental Medicine & Child Neurology*, *59*(5), 470-476.

Core Tenets	Considerations
Health is an emergent set of developmental capacities	Health development occurs through person–environment transactions that are influenced by a person's interests, priorities, social relationships, opportunities, and life experiences
Health develops continuously over the lifespan	Health development is a continuum that includes four phases (generativity, acquisition, maintenance, and managing decline). Importance of sensitive and transition periods
Health development is a complex, nonlinear process occurring in multiple dimensions, and at multiple levels and phases	Person–environment indicators of readiness for change. Determine what needs to occur (modifiable factors) to achieve desired social participation and time interventions accordingly
Health development is sensitive to the timing and social structuring of environmental exposures and experience	Timing and social structuring of opportunities, choices, and ‘real-world’ experiences determine whether person–environment transactions positively or negatively influence health development
Health development is an adaptive process that has been engendered by evolution with strategies to promote resilience and plasticity in the face of changing and often constraining environmental contexts	Health development is an adaptive process in relation to changing and constraining contexts. Importance of considering the ‘fit’ between the person–environment and whether adaptation is required
Health development is sensitive to the timing and synchronization of molecular, physiological, behavioral, social, and cultural function	There are differences in timing and synchronization of development of biological, psychological, cognitive, and social systems. Timing and coordination of formal and informal support systems are critical to the development of health capacity

There is a good body of research that looks at the LCHD model and its application with respect to autism services and supports. Of note is that much of what we know about its application here focuses on the attainment of skills that represent success in one’s transition into adulthood, yet focus less on subjective quality of life aspects.[56] It is here that exploring the Independent Living model, with its focus on holistic and disability-led leadership, may help address some of these gaps.

Independent Living Model

In terms of best practices within any service delivery model, what may be of use is to borrow and/or adapt from models that have successfully served the cross-disability community. This provides the potential to combine successful aspects of the hub and spoke model and/or LCHD model, but to adapt these through a disability specific lens. As some of the key benefits of the hub and spoke model include agility and efficiency, it does seem to lend itself to be individualized and adapted in unique ways. As well, there is nothing in the LCHD model, with its focus on life course and coordination, that isn't enriched by the IL philosophy.

The Independent Living (IL) philosophy of service delivery operates in Canada for the cross-disability community, in ways that are both similar and compliment the hub and spoke model, yet through an important and inclusive disability specific lens. The IL movement is grounded in the idea that people are the best experts in their own needs. This movement, often facilitated through support systems and services and advocacy, has played an important role in ensuring the right of persons with disabilities.[57] While worldwide, the Canadian context for this moment and service delivery may be of use. In Canada the IL movement is comprised of a national office, which represents the voice of the movement nationally, and regional and local IL Centres across the country, which deliver supports and services to people with disabilities, families, and their communities. Through accreditation and core programs (which each IL centre must provide), the national office, and member IL Centres can deliver and serve their community with some standardization through core programming, while also adapting to the needs of users in various regions, without duplicating other services. As an example, each IL Centre operates using the following core programs (reflected through local service delivery and support):[58]

1. Information and Networking: As choices are centred on having access to information, each IL Centre has and information and networking program for users (individuals, families, governments, communities, etc.) that provides plain language, up-to-date, and clear information.

2. Peer Support: Each IL Centre offers opportunities for individuals to connect, support each other, and share their lived experience. This decreases isolation, builds peer

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[56] Drmic, I. E., Szatmari, P., & Volkmar, F. (2018). Life course health development in autism spectrum disorders. In *Handbook of life course health development* (pp. 237-274). Springer, Cham.

[57] McCrary, L. K. (2017). Re-Envisioning Independence and Community: Critiques from the Independent Living Movement and L'Arche. *Journal of Social Philosophy*, *48*(3), 377-393.

[58] Independent Living Canada (2019) Our Programs. Available at: https://www.ilcanada.ca/programs.html

networks, and develops leadership and social skills. It is offered both on a one-on-one basis, or as a group, depending on an individual's needs and comfort level.

3. Research & Community: Grounded in a participatory model, this centres research and learning on identifying community gaps and resources from a grassroots level and grounding responses and solutions in this knowledge and these needs. While these efforts are diverse and individual in each centre, it can include things like accessibility audits and awareness training.

4. Skills Development: This program operates to help individuals gain the skills and confidence necessary to advocate on their own behalf and allow them to take risks based on their choices and decisions. To enable this, learning opportunities and skills development are offered so individual can grow in areas they have identified as a need.

These core programs ensure the IL centres, which operate across the country, are guided by core programming and principles. A benefit of this model is that it is adaptable and can be individualized, and that it is cross-disability in scope - meaning that people with all kinds of disabilities (and their allies) can be supported through these efforts. While not formally a hub and spoke model, the similarities here in terms of structure, user needs (including those with complex disability and communication needs), and work with allied services and supports provide a successful and proven framework that is adaptable. Additionally, the focus on avoiding duplication is appealing as it provides a framework to assess needs and existing resources in ways that avoid time and effort reinventing the service delivery wheel.

These core programs also offer some insight into how to navigate and plan for existing spaces within the delivery of supports and services where there are tensions. Specifically, the following:

1. While there are noted tensions between individuals and parents, especially as they age, the IL model currently supports individuals and other stakeholders in ways that prepare individuals with disabilities to take on greater autonomy as they age;

2. Research that looks at the life course speaks to the success of peer-led initiatives,[59] so there are opportunities to maximize autonomy and support through peer networks in ways that may best serve a person with a disability as they age. Here as well, emerging research points to the potential for peer-support models with respect to supporting individuals with autism, as peer support can provide opportunities to nurture and celebrate development and position autistic people as role models.[60]

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[59] Grossman, B. R., & Magaña, S. (2016). Introduction to the special issue: family support of persons with disabilities across the life course.

[60] Bertilsdotter Rosqvist, H. (2019). Knowing what to do: exploring meanings of development and peer support aimed at people with autism. *International Journal of Inclusive Education*, *23*(2), 174-187.

As IL as a service philosophy exists outside of IL Centres and has been adopted by many service providers, there are potential opportunities to use some of these successful approaches to enhance service delivery, specifically services that are aimed at supporting vulnerable populations and service models that take into consideration the needs of multiple stakeholders (parents, users, medical professionals etc.). Of interest here are findings from a recent brief in Ontario which broadly examined the IL sector (outside of IL centres) and found the following:[61]

- IL programs and services are well positioned to respond to unmet needs and the demand for services through this model are high;
- IL remains more cost effective than some traditional models like hospitals;
- There is real value in this type of model for both the system and individual.

Specific to serving the autism community, research also supports the need to do the following:[62]

- Make written material less complex;
- Provide flexible program delivery;
- Enable strong parent-therapist relationships (to overcome tension and power dynamics);
- Include the extended family;
- Assist families in integrating intervention within their preexisting routines.

These specific considerations when crafting support systems for persons with autism and their families can easily be integrated into the design of a hub and spoke model, especially one that draws from best practices (like IL) from the disability supports and services sector.

Summary of Insights

Reflecting on the literature above, and given the needs of diverse users, and shifting terrain in terms of services and funding, adaptability and efficiency of the hub and spoke model may be a useful model in terms of addressing existing support gaps. Additionally, this model may provide opportunities to address specific gaps, including a lack of support over the life course with integration of core tenets from the LCHD model. The LCHD model also answers some key concerns with respect to the coordination of care and what success here should look like over the life course and across those issues which make up an individual's overall quality of life. While not specifically designed for the disability community, there is potential to serve those within this community with unique support needs, and the integration of a specific disability lens here may be helpful in adapting this model to best serve stated needs. Here, a model grounded in lived experience, like the IL model, offers some insight in terms of how core programs and/or philosophies can help create consistency and cohesion in service delivery,

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[61] Williams, P (2017) Building Community Based Capacity to Meet Ontario's Needs: a brief from the Ontario Association of Independent Living Service Providers.

[62] Pickard, K. E., Kilgore, A. N., & Ingersoll, B. R. (2016). Using community partnerships to better understand the barriers to using an evidence-based, parent-mediated intervention for Autism Spectrum Disorder in a Medicaid system. *American journal of community psychology*, *57*(3-4), 391-403.

while still allowing for diversity in programming to adapt to meet individual, community, and stakeholder needs.

Integrating key aspects of these models not only provides access to successful service delivery components, but provides some philosophical foundations that can proactively address existing tensions between people with disabilities and family caregivers, as well as incorporate a life course model that is attentive to holistic and nuanced aspects of quality of life. Most notably, support with one's need for autonomy, independence, and control over decision making while one ages. Indeed, any successful service delivery model must account for the individual and a supportive process that allows them to grow in these ways.

In terms of moving forward with a hub and spoke delivery model, the literature does provide some insight in terms of recommendations for existing and new models. These include:[63]

- As funding changes and cuts can impact consistency and continuity, there is a need for contingency planning to help reduce the impact of these changes on vulnerable populations.
- Manage how data and information is shared between hub and spokes, including bi-directional flows of information, access to databases, and policies around information sharing.
- As the model seems to be adaptable to extending reach across geographic areas and to various marginalized groups, there is a need to work to build in support to ensure spokes are not isolated and/or excluded.
- Technology can provide an important role in how we share expertise and knowledge between the hub and spokes. It should be integrated and utilized.
- Where multi-agency collaboration occurs, it is important to consider how the hub interacts with the spokes to ensure there is no overshadowing of identity.
- Ensure service users' participation is an integral part of the design, delivery, and monitoring of services. This participation should be meaningful.

Coupled with this, a recent survey in Ontario with families who have children with autism (summer of 2018) makes the following key recommendations:[64]

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[63] Bostock, L., & Britt, R. (2014). Effective approaches to hub and spoke provision: a rapid review of the literature.

[64] McLaughlin, J. & Scheider, M. (2019) autism Services in Ontario: Impacts on Family and Child Well-Being Research Summary.

- Wise and sufficient investment in key areas of service (early diagnosis, respite, augmentative and alternative communication (AAC) if required, education, and therapies). This was found as preferable to funding that diminishes any one area by combining funding envelopes and working across service silos.
- Findings indicate that one factor potentially driving up the cost of Ontario Autism Program (OAP) is insufficient programming for both education and respite. If/when other programs receive adequate support, this helps to alleviate the demand for more costly and individualized services like OAP. A strategy is needed that supports all these areas and ultimately brings down overall cost while still being responsive to needs.

- An evidence and needs based system that can operate within the existing budget, including wrap-around supports, and required therapies, that does not combine non-therapeutic services to ensure services are effectiveness and standardization.

While one may agree or disagree with these key recommendations, one important take-away here is that a hub and spoke model of service delivery could theoretically help address these needs and provide efficiency and cost-effectiveness to the system while still adapting to provide needed and individualized supports. There is an opportunity then to adapt the hub and spoke model in specific ways that practically and philosophically address existing gaps through a re-imagining of the hub and spoke model.