

OAAI Final Report 2021 – Plain Language Version

~ translation by *Sheila Bell, MHSc, Speech-Language Pathologist* ~
(with input from OAAI steering committee members)

The Ottawa Adult Autism Initiative (OAAI) is a local group that includes adults on the autism spectrum, family members and friends, and autism professionals. **Autism Ontario** is OAAI's partner in this project. The project is funded by a grant from the **Ontario Trillium Foundation**.

The goal of this project was to talk to the local adult autism community in Ottawa. We wanted to find out what the lives of adults on the autism spectrum are like right now. We asked “What’s working?” and “What’s not working?” and “What do you need to live a better life?”

We gathered information using **online surveys** and **virtual meetings and interviews**. We heard from more than 400 people in the Ottawa adult autism community.

We hired two consultants to help us carry out this community consultation:

Helen Ries (Great River Consulting Ltd)
Cathy Robinson (Allium Consulting Group Inc)

This report gives you a summary of the results of our community consultation. It is based on the longer report that was written by our project consultants.

Who Answered Our Survey Questions? (p. 4 – 6)

Adults on the autism spectrum:

- Ages 18-60+ (half were aged 25-39, only a few were over age 60)
- Most adults chose to answer the English language survey; most also chose the “text and picture” version of the online survey
- Over 80% described themselves as verbal (able to “talk a lot”)
- Adults were asked about other ways they communicate - many said typing & writing, drawing or pointing to pictures. A few said they use sign language or gestures

Family members and allies:

- This group answered questions about a family member or close friend who is an adult on the autism spectrum
- Some of these answers gave us more information about the nonverbal and less verbal adults on the autism spectrum (34% of the adults described in this group were only able to “talk a little” or “not able to talk”)
- Many of the less verbal adults communicate by typing or sign language, writing, drawing and pointing to pictures/words

Professionals who support adults on the autism spectrum:

This group answered questions about the adults they provide supports and services to.

Report Findings (p. 7 – 35)

The consultants organized the results of our community consultation into 7 themes:

Theme 1 (p. 7 – 10): Adults on the autism spectrum may have no connection (or only a little connection) to support agencies and organizations. Available services often don’t match what adults say they need.

- ASD adults mostly use agencies for social/recreation programs and employment support
- ASD adults also use agencies to access funding supports

Conclusions:

- Funding rules are complicated. It can be difficult to get through the application process & many ASD adults don’t qualify for funded supports and services
- It is difficult for ASD adults and their families to find supports and services that match their needs. Adult autism services in Ottawa are not connected to each other right now. A connected network of supports/services with one entry point would make it easier for ASD adults to find what they need.

- Services need to be developed to match what ASD adults are looking for (for example, developing individualized housing plans and supports for independent living)
- Less verbal ASD adults and older (40+) adults need more services that fit their specialized needs. We need to gather more information about these parts of the adult autism population.

Theme 2 (p. 11 – 15): Many adults on the autism spectrum want to work (both paid work and volunteer work). They also want to study and learn new things. There are not enough programs to help adults reach these goals.

- Most ASD adults stay at home during the day. Most would like to do something else as well, or something else instead of staying at home.
- ASD adults want a balance of activities in their lives (work, education, recreation, relaxation)
- COVID-19 lockdowns have changed/reduced the possible choices for daily activities

Conclusions:

- A good network should match supports and services to the real wants/needs of ASD adults.
- Education and employment help people to feel valued in their community. Paid jobs lead to financial independence.
- Community education about autism (for employers and educational institutions) is important to create opportunities.

Theme 3 (p. 16 – 19): Adults on the autism spectrum face challenges in taking care of their physical and mental health. They need professionals in all health services who understand autism.

- “Professionals who understand autism” is the number one need identified by ASD adults, family members and professionals (to help ASD adults take care of their physical and mental health)
- “Stress and anxiety” is the most common mental health problem reported by ASD adults (76%) and observed by their family members (94%)
- ASD adults need money to access health services (especially mental health services, which are often offered by private practice professionals)

Conclusions:

- A good network will include ongoing autism education for health professionals and service providers (also other professionals like lawyers, who may become involved in health and well-being issues).

- ASD adults may need direct support with coordinating and getting to health appointments.
- Mental health assessment and support is important for ASD adults
- A better general understanding of autism will help Ottawa to become an autism-friendly community

Theme 4 (p. 20 – 22): Adults on the autism spectrum want to make decisions about their lives. They need help to do this.

- ASD adults need support to develop problem-solving skills – this will help them to make better decisions
- Less verbal ASD adults need support with alternate communication methods, so they can let others know what they want and what they don't want
- All ASD adults should be supported to make as many of their own decisions as possible

Conclusions:

- Having a say in important decisions contributes to quality of life
- A good network will support ASD adults in making important life decisions. This will be a central guiding principle.
- Decisions can become more complicated as an ASD adult gets older (for example, they may have to support and care for elderly parents)

Theme 5 (p. 23 – 25): Adults on the autism spectrum and their families worry about the future. To feel more secure, adults need a plan, money, friends (support network) and a home.

- Most ASD adults do not feel good about their future
- ASD adults and their families are uncertain that they will have enough money, a personal support network (friends/close relationships), a plan and a home of their own
- In the small group meetings, people suggested a “systems navigator” – someone who could help ASD adults find services that meet their individual needs (this will only be helpful if needed services exist)

Conclusions:

- Everyone needs a secure future. ASD adults are vulnerable and need help to make sure they have enough money, a personal support network and a home
- A good network will include financial and other special resources (for example, lawyers who understand autism) to help ASD adults and their families make strong future plans
- Security and safety are important for ASD adults of any age. This will be a central principle in designing a network.

Theme 6 (p. 26 – 30): Each adult on the autism spectrum needs a housing plan that fits their needs. Housing that works means a better life right now and a better life in the future. There are many challenges that make it difficult to reach this goal.

- Most ASD adults live with their families
- An individualized housing plan is important for a good quality of life now and in the future
- Family members who are primary caregivers for ASD adults worry about who will take on the caregiver role for their son/daughter in the future
- Caregivers need support to find solutions: financial, respite, a network of caregivers

Conclusions:

- Stable and affordable housing that fits the needs of the individual ASD adult is a basic human right. It is key to a secure future. There are many barriers to finding the right housing solution in the Ottawa area.
- It's important to increase community understanding about the needs of ASD adults (especially among housing providers)
- ASD adults need individualized housing plans to match their specific needs

Theme 7 (p. 31 – 35): Professionals who support adults on the autism spectrum offer a variety of supports and services. There are not enough services for the number of adults who need them. Many services are only offered to verbal adults and adults with less complicated needs.

- Professionals work mostly with verbal ASD adults who don't have severe behavior or mental health challenges
- Professionals who work with agencies/organizations offer mostly social and recreational support
- Professionals identified these important needs: more funding, more mental health supports, supportive housing, and a centralized network where ASD adults could easily find the services they need

Conclusions:

- Match services to the needs of ASD adults. Support development of services to fill gaps
- Better funding so ASD adults can afford the services they need
- Emphasis on programs that focus on housing, employment, future planning (things that will help build a satisfying life and a safe and secure future)
- Supports and services for ASD adults with more complex needs: non-verbal/less verbal, severe behaviour or mental health challenges

Overall Conclusions and Final Thoughts (p. 36 – 38):

Many members of the Ottawa Adult Autism Community responded to our surveys, small group meetings and personal interviews. People want to make our community a better place for adults on the autism spectrum. This project is the first step.

We need a system that is easy for ASD adults and their families to navigate. It must be responsive to the changing needs of the Ottawa adult autism community:

- One entry point for all adults on the autism spectrum
- Personal support to go through the process of asking for help and connecting with supports/services that match individual needs
- Constant feedback from system users to identify gaps in service
- Support to professionals and agencies to develop missing services

We also need to provide on-going education and outreach to the local community on the topic of autism. Adults on the autism spectrum will do better if the people they interact with in the larger community have a good understanding of autism (eg. health professionals, legal professionals, government officials, law enforcement, employers, co-workers, etc). We want Ottawa to become an “Autism-Friendly City”.

We need to continue gathering information about the needs and priorities of ASD adults who are part of the following groups (under-represented in this initial consultation):

Nonverbal / Less Verbal

Older (40+)

Francophone

LGBTQA2S+

Indigenous people

Newcomers to Canada

Rural residents

Visible minorities

We can support a secure future for ASD adults by creating a secure present.

Six “Snapshots” are listed in report Appendix A (p. 39 – 55). These give a closer look at some important topics:

Snapshot 1: Home Life (p. 40)

Snapshot 2: Physical Health (p. 41)

Snapshot 3: Mental Health (p. 42)

Snapshot 4: Decision Making (p. 43)

Snapshot 5: Non-Verbal / Low-Verbal ASD Adults (NVLV) (p. 45)

- Most NVLV ASD adults:
 - can talk a bit
 - are connected to autism-supportive agencies
 - stay home most of the day
 - live with family
- Almost all NVLV ASD adults have had their activities severely affected by COVID-19
- NVLV ASD adults
 - face multiple barriers to doing more activities in the community
 - need appropriate housing choices to improve their home life
 - face challenges and barriers to accessing health care
 - face multiple barriers to social and personal relationships
- Most family/allies say the NVLV ASD adults do not make big decisions about their life. The biggest barrier is lack of tools to communicate decisions
- NVLV ASD adults face significant barriers to a secure future (including a caregiver to take over when a parent is no longer able to help)

Snapshot 6: ASD Adults Age 40+ (p. 50)

- Most older ASD adults:
 - are not connected to ASD-supportive agencies (few receive services or funding)
 - live with others (non-family) or alone
 - were diagnosed as adults (half by doctors, half self-diagnosed)
 - make all the important decisions about their lives
- Here’s what older ASD adults say would help:
 - more money (stable/steady income)
 - affordable secure housing choices
 - support with developing/maintaining close relationships
 - job/employment support (want to work, also have to work for financial reasons)
 - support with problem-solving (need skills to make good decisions)
 - support to manage physical and mental health (financial, professionals who understand autism, sensory-friendly medical offices)
- Half of older ASD adults are worried about their future