

Aging and Autism: Community Insights and Research Synthesis

(Plain Language Summary)

Funding was provided by the Government of Newfoundland and Labrador's Age-Friendly Newfoundland and Labrador Program Stream 1.

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Plain Language Summary

What is this report about?

Autistic people grow older, just like everyone else. However, much of the research about autism has focused on children and younger adults. There is much less research about what it is like to age as an autistic person.

This project looked at two things:

1. What autistic adults and caregivers in Newfoundland and Labrador said about aging and autism.
2. What existing research tells us about autism and aging.

The goal was to better understand the concerns, priorities, and information needs of the autism community and identify areas where more research is needed.

What did the community tell us?

Two surveys were shared with the community: one for autistic adults and one for people who provide care to autistic adults.

Who responded?

- 56 autistic adults completed the survey.
- 70 caregivers completed the caregiver survey.

The survey was voluntary and was shared through social media, ASNL's email list and word of mouth. The results are intended to help identify community perspectives and priorities. They are not intended to represent every autistic person or caregiver.

What are autistic adults concerned about as they age?

Autistic adults identified a number of concerns about their own aging.

The most commonly selected concerns were:

- Finances (38%)
- Mental health and emotional well-being (34%)
- Forming and maintaining social relationships (27%)

Autistic adults were also asked about concerns related to their caregivers getting older. Some of the most common concerns were:

- The emotional impact of watching a caregiver age (25%)
- Financial security (23%)

These responses show that aging can involve many different kinds of concerns, including financial security, relationships, mental health, and changes in family or caregiving relationships.

What are caregivers concerned about?

Caregivers identified several major concerns about the future. The most common were:

- Planning for the future of their autistic loved one (97%)
- Being able to continue providing care (71%)
- Their own mental health and emotional well-being (46%)

Caregivers also identified concerns about what would happen to their loved one if they were no longer able to provide care. Other concerns included:

- Housing security
- Transferring care to someone else
- Adult friendships and relationships
- Having enough information and resources to plan for the future

What areas should future research focus on?

Autistic adults and caregivers identified several areas they believe need more research.

Autistic adults' priorities

The most commonly selected areas were:

- Access to healthcare and services (54%)
- Mental health in later life (54%)
- Housing security (45%)
- Cognitive change (39%)
- Employment (36%)

Caregivers' priorities

The most commonly selected areas were:

- Housing security (63%)
- Aging caregivers (59%)
- Social connection (53%)
- Access to healthcare and services (51%)
- Employment (49%)

There is a lot of overlap between these priorities. Healthcare, housing, employment, social connection, and planning for the future are important areas for both autistic adults and caregivers.

What did people say about finding information?

Many people said they had difficulty finding information about autism and aging. For both autistic adults and caregivers, the most common places they had learned about autism and aging were:

- Autism organizations and community organizations
- Social media

However, 29% of both autistic adults and caregivers said they had not encountered any of the listed resources about autism and aging.

People also reported barriers to accessing research and other resources. The most common barrier was cost. Other barriers included:

- Difficult or unclear language
- Jargon
- Unclear formatting
- Not knowing where to find relevant information
- Not having enough time to look through research and resources

This suggests that it is not enough for research to exist. Information also needs to be free or affordable, easy to find, understandable, and useful in everyday life.

What kinds of resources do people want?

People were asked what types of resources they would find most useful. For both autistic adults and caregivers, practical guides were the most popular choice. Other commonly selected options included:

- Plain-language summaries
- Toolkits
- Infographics

This is important because academic research can be difficult to access and understand. Community members told us that they want information they can actually use.

What does existing research tell us?

The report also reviewed existing research about autism and aging. The research review provides a snapshot of existing research and some of the gaps that still need to be addressed. Several major themes emerged:

Mental health

Mental health was an important concern for both autistic adults and caregivers. Research suggests that autistic adults experience mental health conditions at higher rates than non-autistic adults. However, mental health experiences are not simply a result of being autistic.

Several factors can negatively affect mental health and may contribute to autistic burnout. Some of these include:

- Stigma
- Social exclusion
- Bullying
- Loneliness
- Masking
- Lack of support

Research also suggests that autistic identity, social connection, and feeling accepted can have positive effects on well-being. More research is needed to understand how mental health changes throughout the lifespan and how healthcare and mental health services can better support autistic adults.

Physical health

Research suggests that autistic adults may experience higher rates of some physical health conditions than non-autistic adults. There are also concerns about sleep, physical activity, and access to appropriate healthcare.

Some research suggests that autistic adults may experience higher rates of premature mortality, particularly autistic adults who also have an intellectual disability. However, much more research is needed to understand why these differences occur and how they can be addressed.

The report also highlights gaps in research about:

- Menopause
- Menstruation
- Autistic women
- Autistic transgender and non-binary people
- Autistic adults with intellectual disabilities
- Other intersecting identities and experiences

Access to appropriate healthcare is an important part of improving health outcomes.

Healthcare and services

Access to healthcare and services was one of the strongest themes in both the community survey and the research.

Autistic adults may experience barriers when trying to access healthcare, including:

- Difficulty navigating complicated systems
- Communication differences
- Sensory environments that are overwhelming
- Unexpected changes or delays
- Physical touch during examinations
- Healthcare professionals who have limited knowledge about autism
- Difficulty recognizing or communicating physical symptoms

Research suggests that healthcare systems need to become more accessible and autism-informed. This includes better training for healthcare professionals, more accessible healthcare environments, and practical resources that help autistic adults navigate healthcare.

Social connection

Social connection can look different for different autistic people. Some autistic adults experience loneliness and difficulty maintaining relationships. Research suggests that loneliness can increase with age and may be associated with poorer mental health and well-being.

At the same time, autistic people have different preferences for social interaction. Some people may want many social connections, while others may prefer fewer or different types of relationships.

Connections can happen through:

- Friendships
- Romantic relationships
- Family
- Shared-interest groups
- Online communities
- Autism-specific groups
- Neighbourhood activities
- Community organizations

Research should recognize this diversity instead of assuming that everyone has the same social goals. More research is also needed about how major life changes, such as retirement, menopause, or the death of a parent, can affect relationships and social connection.

Employment and retirement

Employment is connected to quality of life for many autistic adults, but unemployment and underemployment remain significant concerns. Research has also identified strengths that autistic adults may bring to the workplace, including:

- Attention to detail
- Pattern recognition
- Ability to work independently
- Dedication

- Honesty
- Strong interests and knowledge

Workplace support, acceptance, and finding a good fit between a person's interests and their work can also affect job satisfaction.

There is very little research about retirement and autistic adults. Retirement can involve major changes to routine, identity, finances, and social connections.

Housing

There is limited research about housing and residential care options for autistic adults. Research that does exist highlights the importance of:

- Autism-informed staff
- Individualized sensory accommodations
- Quiet and comfortable environments
- Opportunities for community and connection
- Involving autistic people in decisions about residential care

What are the biggest gaps in research?

The report found that there is still a lot we do not know about aging and autism. Some of the biggest gaps include:

- Most research focuses on children and younger adults, with limited research involving people aged 60 and older.
- Following autistic people over time would help us better understand how experiences change throughout aging.

Research should be intersectional and include autistic people with different:

- Gender identities
- Sexual orientations

- Racial, ethnic, and cultural backgrounds
- Socioeconomic backgrounds
- Levels of support needs
- Communication styles
- Intellectual abilities

We need better ways to identify autism in older adults.

Some autism assessment tools were developed using younger people. They may not always accurately capture how autism presents in older adults.

We need to listen to autistic people throughout the research process.

Autistic people should not only be included as research participants. Their knowledge and lived experience should help shape research questions, study design, interpretation of findings, and how information is shared.

What does this mean going forward?

The report points to a clear need for more research about autism and aging, but research alone is not enough. The information produced through research also needs to reach the people who could use it. The community told us that resources should be:

- Accessible
- Free or affordable
- Easy to find
- Written in plain language
- Practical
- Relevant to everyday life

Research should also be developed with autistic people and the broader autism community, rather than simply being done about them.

Conclusion

Autistic people are aging, but research and services have not kept pace.

The community survey highlighted concerns about healthcare, mental health, housing, employment, social connection, finances, and planning for the future. The research review showed that these are also areas where significant gaps remain.

There is no single experience of aging as an autistic person. People have different needs, preferences, identities, strengths, support needs, and goals.

Future research and services need to reflect that diversity.

Most importantly, autistic people need to be involved in shaping the research, resources, and services that affect their lives.