

Aging and Autism: Community Insights and Research Synthesis

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There is considerable diversity within the autistic community in how individuals and communities understand and identify themselves, reflecting varied experiences and identities (Botha et al., 2022; den Houting, 2019). Neurodiversity refers to the natural variation in human neurological functioning and challenges assumptions that there is a single normative way of thinking, communicating, learning, sensing, regulating, or relating. From a neuro-affirming perspective, autism is understood as a neurodevelopmental difference and a form of human diversity, rather than being conceptualized solely through a deficit-based lens as a collection of impairments that need to be corrected (Botha et al, 2022; Walker, 2021). This perspective does not deny support needs that autistic people and their families may have; rather, it recognizes that experiences of disability are shaped through the interaction between neurocognitive differences, social and relational environments, policies and access to appropriate supports.

From a clinical perspective, autism can be broadly described as a neurodevelopmental condition characterized by persistent difficulties with social communication and interactions across multiple contexts along with the presence of repetitive and restrictive behaviors and interests (American Psychiatric Association, 2022). Autism is lifelong, yet a large portion of existing research focuses primarily on the experiences of autistic children. Comparatively, autistic adults are underrepresented in the existing literature base with this gap being even more prevalent in research concerning seniors/older adults – with a recent review finding that only ~ 0.4% of publications regarding autism since 2012 have focused on autism in older adults (Mason et al., 2022). This disparity is particularly concerning as most autistic individuals are adults (Stewart et al., 2026).

In Canada, it is estimated that autistic adults make up roughly 1.8% of the population, with a 2% prevalence estimate in Newfoundland and Labrador specifically (Collins et al., 2025). Furthermore, it is estimated that up to 90% of autistic individuals over the age of 50 are undiagnosed, meaning these numbers are likely significantly higher (Stewart & Happé, 2025). These estimates demonstrate that a substantial number of Canadian adults are autistic, yet there is a major gap in understanding their needs and unique experiences. Additionally, with a further estimated 2.25% of Canadian children meeting the diagnostic criteria for autism (Public Health Agency of Canada, 2025), a large cohort of autistic youth will soon transition into adulthood relying on healthcare systems, care facilities, and social services that do not yet fully understand them and therefore cannot fully support their needs.

Autistic adults may experience distinct aging trajectories, thought to be shaped by neurodevelopmental differences as well as social and environmental factors (Stewart & Happé, 2025; Stringfellow et al., 2024). While there is a promising increase in research concentrating on older autistic individuals (see Mason et al., 2022), there remain significant gaps in our understanding. The focus of the current project was to identify and explore research, initiatives, and community perspectives related to autism and aging. The goal was to bring together scientific research, community resources, and voices from within the autism community to form a more comprehensive understanding of aging with autism that recognizes the variance and value of lived experience and outlines actionable goals and priorities for future research. The following report begins with the results of a survey that was used to explore the concerns, knowledge, and priorities for future research identified by autistic adults and caregivers and ends with the results of an informal literature review on existing academic resources that address autism and aging.

Community Perspectives

To gather perspectives and opinions from the autism community, we developed two brief surveys: one for autistic adults and one for individuals who provide care to autistic adults (referenced throughout this report as “caregivers”). These surveys were designed to capture an overview of aging-related concerns, research priorities, and considerations for knowledge dissemination as identified by the people who stand to benefit the most from research on aging with autism. Importantly, these surveys were implemented as exploratory, descriptive, tools used *not* as a way to test a direct hypothesis, but to inform a subsequent literature review of existing research in this area. These surveys were intended to specifically inform an understanding of *autism and aging*.

Survey Administration

The survey was co-constructed and distributed through the Autism Society of Newfoundland and Labrador. Given that this survey is part of community and services provision, no ethics approval was needed. Participants were recruited through social media (e.g., Facebook) and word of mouth. Participation was voluntary, with no incentives provided. Participants could withdraw from the survey at any time prior to the submission of their responses. Respondents included autistic adults and caregivers, with different versions of the survey for each demographic. Basic, optional demographic data including age and gender identity was collected. The survey was administered online via Google Forms and multiple responses were permitted for each question. Additionally, each question was accompanied by an open textbox option and the survey concluded with a general open textbox prompt in order to allow space for respondents to elaborate on their responses or express concerns that were not covered by the survey questions.

Demographics

Autistic Adults

Fifty-six autistic adults responded to the survey, with 37 females, 11 males (including one transgender male), and 7 non-binary individuals (including one trans-masculine individual). The mean age of respondents was 36.4 ($SD_{age} = 12$). Of this sample, 75% reported at least one co-occurring condition with ADHD (52% of sample), anxiety (32%), and depression (23%) being the most commonly reported.

Caregivers

The caregiver survey received 70 responses, 58 were female and 12 were male ($M_{age} = 48.7$, $SD_{age} = 12$). Of this sample, 26% reported at least one mental or physical health condition with the most commonly reported being ADHD (16%) and Anxiety (7%).

Aging Concerns

Respondents identified a wide array of age-related concerns. Amongst autistic adults, the most commonly identified concerns included worries surrounding finances (38%, $N = 21$), mental health and emotional wellbeing (34%, $N = 19$), and forming/maintaining social relationships (27%, $N = 15$). Caregivers overwhelmingly reported concerns related to planning for the future for their autistic loved ones (97%, $N = 68$), their continued ability to provide care (71%, $N = 50$), and for the caregiver's own mental health and emotional well-being (46%, $N = 32$).

The most commonly identified concerns of autistic adults related to the aging of their caregiver included the emotional impacts of watching their loved one's age (25%, $N = 14$) and financial security (23%, $N = 13$).

Research and Resources Regarding Autism and Aging

Both autistic adults (50%, N = 28) and caregivers (49%, N = 34) reported that they had most commonly learned about research/resources regarding autism and aging through autism-specific organizations/community. The other most common source of information for both groups was social media (autistic adults: 41%, N = 22; caregivers: 31%, N = 22). Other sources included healthcare professionals (autistic adults: 25%, N = 14; caregivers: 31%, N = 22), peers (autistic adults: 21%, N = 12; caregivers: 27%, N = 19), and academic papers (autistic adults: 29%, N = 16; caregivers: 14%, N = 10). Notably, a high percentage of respondents indicated that they had not encountered any of these resources (autistic adults: 29%, N = 16; caregivers: 29%, N = 20).

This reported lack of exposure to existing sources is likely indicative of persistent challenges with accessing research and the barriers that limit individuals' ability to engage with these resources. In line with this idea, we asked respondents to identify the barriers they had personally encountered in accessing research and other initiatives. The most commonly identified barrier for both autistic adults (43%, N = 24) and caregivers (36%, N = 25) were the costs and fees required to access research and services. Another commonly identified challenge was barriers in communication (e.g., jargon/difficult terminology, unclear formatting, etc.) with 30% (N = 17) of the autistic adult sample and 26% (N = 18) of the caregiver sample reporting this as an obstacle they had encountered. Importantly, a number of respondents indicated via the open textbox that they simply did not know where or how to access relevant research or that they lacked sufficient time between responsibilities to explore these resources for themselves.

Priorities for Future Research

Respondents were also asked to select the areas of research on aging and autism that they believed should be prioritized. The top five most commonly selected response options among

autistic adults were the accessibility of healthcare and services (54%, N = 30), mental health in later life (54%, N = 30), housing security (45%, N = 25), cognitive change (39%, N = 22), and employment (36%, N = 20). For caregivers, the top five responses were housing security (63%, N = 44), aging caregivers (59%, N = 41), social connection (53%, N = 37), accessibility of healthcare and services (51%, N = 36), and employment (49%, N = 34).

Lastly, respondents were asked what kind of final product developed from this project would they find most useful. While this question was largely specific to the current project, we felt that the results could be informative for future knowledge dissemination in this area. The most common responses for both autistic adults and caregivers were practical guides (autistic adults: 57%, N = 32; caregivers: 76%, N = 53), plain language summaries (autistic adults: 52%, N = 29; caregivers: 40%, N = 28), toolkits (autistic adults: 36%, N = 20; caregivers: 57%, N = 40), and infographics (autistic adults: 46%, N = 26; caregivers: 13%, N = 9).

Additional Comments

The survey concluded with an open textbox where participants were invited to share any additional topics or issues that they hoped we could address in our literature review. Autistic adults reported a need for support with late diagnoses and higher needs, as well as help with organization and daily life skills. Caregivers expressed concerns regarding housing security for their loved one, transferring care of their loved one to someone else in the event of their passing, and needing more resources regarding adult relationships and friendships for autistic individuals.

Discussion

The results of the present survey suggest that autistic adults and caregivers primarily require information related to practical concerns such as housing, healthcare, and planning for the future. Additionally, there was concern regarding the barriers to accessing research,

emphasizing the importance of sharing research findings in ways that are accessible, especially to those who may directly benefit from these findings and may not have a background in research. Lastly, a general preference for resources such as practical guides and toolkits may indicate a potential demand for actionable information.

Literature Review

The following literature review was conducted in order to form an understanding of the current landscape of research on autism and aging by consolidating existing research and materials. This process was influenced partly by the community perspectives expressed in the survey, with special attention paid to high priority areas including mental health, access to services, social connectedness, and cognitive aging. The following is not meant to be an exhaustive review of all existing sources, rather, it is meant to serve as a snapshot of the current scope and trends of research in autism and aging.

Method

Due to the exploratory nature of the present study, the current review was not conducted using a formalized systematic or scoping review process. Instead, we implemented a flexible search strategy to identify relevant publications. These searches were conducted using broad keywords and phrases such as “autism and aging”, “autistic seniors”, “adult autism”, and “neurodiversity and aging”. In some cases, more precise terminology was used to target specific topics identified as areas of interest by the community and relevant sources were added as identified.

Publications were included if they focused on autism or neurodiversity (though research on autism was prioritized for this report) and addressed aging or later life. Sources also had to be peer reviewed, available in English, and fully accessible by the reviewer. A data-extraction grid

was designed to summarize key information from each article including methodology, findings, and any gaps in research (or future directions) identified by the authors. The emerging themes and research gaps established during this review are synthesized below.

Mental Health

Both autistic adults and caregivers emphasized the importance of understanding mental health across the lifespan for autistic individuals. Mental health was a common topic within existing literature on autism and aging, with evidence suggesting that autistic adults experience higher rates of co-occurring mental health conditions compared to non-autistic adults (Croen et al., 2015; Joshi et al., 2012; Klein & Klinger, 2024; Lever & Geurts, 2016; Moss et al., 2015; Stringfellow et al., 2024; Torenvliet et al., 2025; Underwood et al., 2022; Yazar et al., 2022). While estimates vary widely, it is thought that anywhere from 54 - 94% of autistic individuals will develop a mental health condition in their lifetime, with a recent study by Underwood et al. (2022) finding that 47.63% of autistic adults in a population-level health record dataset had at least one diagnosed psychiatric disorder, with ~26% having two or more. Similarly, a study by Hand et al. (2019) concluded that autistic seniors over the age of 65 are more likely than non-autistic adults to be diagnosed with almost all mental health conditions, with especially high rates of schizophrenia, attention-deficit disorders, personality disorders, and suicidality. Other commonly reported conditions include anxiety, depression, and OCD (Hand et al., 2019; Perkins et al., 2012; Underwood et al., 2022).

Despite this high prevalence of psychiatric conditions, several studies identified factors that may positively influence psychological outcomes in later life. Strong feelings of inclusion and social identification with family and other autistic individuals was associated with fewer depressive symptoms (Maitland et al., 2021). Additionally, in a study by Browne et al. (2024),

autistic adults indicated that having a diagnosis of autism contributed positively to their mental health by providing greater clarity regarding one's identity and needs, as well as greater understanding of the context underlying challenging experiences – further evidence suggests that autistic individuals feel more content with their identity as years pass after their diagnosis (Corden et al., 2021). A more positive view of autistic identity was also found to predict higher levels of self-esteem (Corden et al., 2021). Conversely, social factors such as loneliness, exclusion, bullying, stigma, and masking behaviors are associated with worse mental health outcomes and can contribute to autistic burnout (White et al., 2023). Promisingly, there is some evidence that general physical activity and exercise programs may support emotional regulation, reduction in aggressive behaviors and distress, and increases in general well-being. However, this evidence is limited by small sample sizes and generally focused on samples of young adults with co-occurring intellectual disability (ID), making it difficult to make strong conclusions regarding the degree of improvement and long-term effects of physical activity for older autistic adults (Hallett, 2019; Shahane et al., 2023).

Overall, these findings demonstrate that mental health considerations should be a central component of research on autism and aging, with significant work left to be done to address gaps in knowledge. Future directions for research in this area include the development of more effective/inclusive diagnostic tools for both autism in adults *and* co-occurring mental health conditions which may be overlooked due to overlap in symptoms and diagnostic overlap (Amanullah et al., 2020; Curnow et al., 2023). Similarly, a review by Curnow et al. (2023) identified a need to evaluate not simply the effectiveness of various mental health interventions, but also potential adverse effects and harms associated with them. The same review also states that an individual's specific needs, preferences, and communication style should be considered

when creating a treatment plan (Curnow et al., 2023). Additionally, there is a need for more in-depth research into how the use of multiple prescribed treatments for mental health (e.g., antidepressants, anti-psychotics, and anti-anxiety medications) simultaneously (polypharmacy) could affect autistic adults over the course of their lives (Edelson et al., 2020; Yoshida et al., 2024). Lastly, many studies expressed a need for longitudinal research to determine how the symptoms of co-occurring mental health conditions change across the lifespan and what factors affect outcomes (Klein & Klinger, 2024; Stewart et al., 2026a; Yarar et al., 2022). This need for longitudinal research is a theme that echoes across most domains of research on autism and aging.

Physical Health

Autistic adults appear to experience a higher rate of physical health conditions when compared to non-autistic adults. Commonly reported co-occurring physical health conditions include – but are not limited to – cardiovascular conditions, epilepsy, asthma, Parkinson’s disease, and gastrointestinal issues (Bishop-Fitzpatrick & Rubenstein, 2019; Charlton et al., 2023; Croen et al., 2015; Hand et al., 2019; Liu et al., 2023; Torenvliet et al., 2025). As identified in a review by Edelson et al. (2020), these conditions can manifest as ‘harmful and/or aggressive behaviors’ in effort to convey discomfort (e.g., head banging due to migraine headaches), particularly for those who use non-verbal communication styles.

In addition, autistic adults may experience poorer overall physical functioning including poor diet, exercise, and sleep patterns - this could lead to many adverse outcomes including an increase in physical health risks, worsening behavioral issues, and also may contribute to unemployment/underemployment (Weir et al., 2021). Relatedly, problems with sleep are well documented amongst autistic children, and research has begun to emerge demonstrating that

these issues persist into adulthood (Goldman et al., 2017; McLean et al., 2021; Morgan et al., 2020). These sleep issues have been associated with poorer quality of life (QoL) and increased perceived stress (Mclean et al., 2021).

Rates of premature mortality also appear to be elevated for autistic adults (Hirvikoski et al., 2016; Pu et al., 2025), with higher rates for individuals with co-occurring ID (O’Nions et al., 2024). In a study by O’Nions et al. (2024), they found that autistic adults with co-occurring ID had 2.83 times the mortality rate of non-autistic adults, compared to 1.71 times the mortality rate among autistic adults without ID. The estimated reduction in life expectancy was also greater for autistic adults with ID - ~7.28 years for men, and ~14.59 years for women – compared to autistic adults without ID who saw a reduction of 6.14 years for men and 6.45 years for women (O’Nions et al., 2024). Common causes of death include deaths related to epilepsy, accidents (e.g., drowning or suffocation), cancer, neurological disorders, and respiratory disorders (Perkins et al., 2012; Smith DaWalt et al., 2019; Wu et al., 2025).

Evidence suggests that autistic women experience more physical health challenges than autistic men (and non-autistic women) (Kassee et al., 2020). Furthermore, autistic women have the added concern of sex-specific issues such as menopause and menstruation. Menopause represents a significant challenge, with autistic women experiencing higher levels of menopausal complaints, possible increases in autistic characteristics (including sensory sensitivities), and higher levels of depression (Groenman et al., 2021; Karavidas & de Visser, 2021). Despite these heightened experiences, in a qualitative study by Brady et al. (2024) participants reported that they lacked knowledge about menopause both in general, and regarding how the menopausal transition may interact with the autistic experience. This reflects a lack of autism-informed and community led resources and supports for autistic adults experiencing menopause (Brady et al.,

2024; Grant et al., 2026; Jenkins et al., 2024). While information in this area is already limited, our review found no studies that focused specifically on the experiences of autistic transgender or non-binary individuals (assigned female at birth) who may also experience menopause – though this population is included in some studies, samples are generally too small to form any strong conclusions. Autistic adults with co-occurring ID represent another under-researched group in this area.

Priorities for research into the physical health of autistic adults include longitudinal studies that examine the trajectory of physical health to identify where disparities between autistic and non-autistic adults are occurring (Bishop-Fitzpatrick & Rubenstein, 2019). Additionally, a wider array of demographics (e.g., autistic adults with co-occurring ID, LGBTQ+ individuals, and individuals from diverse racial, ethnic, cultural, and socioeconomic backgrounds) should be included in future research to determine how these factors may influence physical health outcomes and how individuals might experience intersecting social identities. Importantly, as identified by Perkins et al. (2012), there are several modifiable, preventive factors that may help optimize the aging process (e.g., health surveillance, health screenings, and careful management of co-occurring physical health conditions). However, many of these factors rely on access to healthcare systems and practitioners that are equipped with knowledge and understanding of the needs of autistic adults.

Access to Healthcare and Services

Concerns regarding access to healthcare and support services appeared in our community survey as a top priority among both autistic adults and caregivers, mirroring concerns expressed throughout the literature and other community-based qualitative reports in Canada (see Salt et al., 2024). Across multiple studies, autistic adults reported great difficulty in accessing

satisfactory healthcare and services for many reasons including a simple lack of formal support, difficulty navigating confusing and disorganized systems, and prohibitive fees (Calleja et al., 2020; Crane et al., 2018; Huang et al., 2022; Nicolaidis et al., 2012) - with autistic adults and caregivers in one UK study (Crane et al., 2018) reporting that services were not made available to them until a point of crisis had been reached. In a study from Nicolaidis et al. (2012) that compared the healthcare experiences of autistic adults to non-autistic adults, autistic adults reported a higher likelihood of unmet healthcare needs including physical healthcare, mental healthcare, and prescription medications.

Autistic adults can encounter a wide variety of challenges in seeking healthcare. One such challenge is differences in communication style which can affect multiple aspects of healthcare including making appointments, communicating with receptionists, and interactions between patients and clinicians (Dern & Sappok, 2016; Nicolaidis et al., 2012; Shaw et al., 2023). This can be further complicated by a reported lack of training for physicians in the care of autistic adults, with only 36% of physicians in one study indicating that they had received *some* training in this area and over half of the same sample indicating that they would like more training (Bruder et al., 2012). Additionally, sensory issues were identified as another major barrier to healthcare access (Dern & Sappok, 2016; Nicolaidis et al., 2012; Raymaker et al., 2016; Shaw et al., 2023). Healthcare environments are often noisy, unfamiliar, overly bright, and crowded - making for an uncomfortable and overwhelming experience for many autistic adults. Similarly, many examinations by physicians require some form of physical touch, a sensation that, for many autistic adults, is incredibly aversive (Stewart et al., 2026b). Furthermore, the unpredictability of these settings (e.g., appointments that begin after the originally scheduled time) was also found to be distressing (Shaw et al., 2023). Finally, evidence shows that autistic

adults may struggle with interoception – the ability to process internal bodily signals such as pain, bodily discomfort, hunger, and temperature (Bonete et al., 2023; Trevisan et al., 2021). This may lead to difficulty conveying health concerns and delays in recognizing symptoms (Palser et al., 2026).

Primarily, future research in this area should continue to identify and draw attention to the barriers to accessing healthcare that autistic adults encounter, as well as the causes that underlie these barriers. Additionally, better training materials for healthcare professionals and clinicians are essential to improving care (Bruder et al., 2012; Crompton et al., 2020; Dern & Sappok, 2016). Further research should be done into how healthcare environments and service procedures can be restructured to be more comfortable/accessible for autistic adults and otherwise neurodiverse individuals (see Hamdan & Bennett, 2024). Alongside improvements to healthcare systems and professional knowledge, it is of equal importance for future research to support the healthcare literacy of autistic adults themselves. This could involve designing and evaluating toolkits and practical guides to facilitate healthcare experiences (e.g., The Sinneave Family Foundation, 2024). Additionally, an interesting avenue for future research could be to evaluate the effectiveness of interoceptive training for autistic adults in healthcare situations. It is also pertinent to consider the broader social determinants of health – including intersecting identities, rurality, and socioeconomic status – and how these factors may shape healthcare experiences and access to services for autistic adults (Barrington et al., 2025; Stewart et al., 2026b; Zhang et al., 2025).

Social Connectedness

Across studies, autistic adults appeared to struggle with forming and maintaining social connections (Billstedt et al., 2010; Gotham et al., 2015; Stewart et al., 2024). Evidence from Stewart et al. (2024) suggests that, for autistic adults, loneliness increases with age. This

loneliness has been shown to be associated with increased depression and anxiety, as well as a decrease in overall well-being (Mazurek, 2013). Conversely, access to social supports has been associated with better QoL in older autistic adults (Charlton et al., 2022). There are a multitude of factors that are associated with decreased social connectedness for autistic adults, these factors include stigma and a lack of understanding from others, sensory avoidance leading to social isolation, and unemployment (Umagami et al., 2022).

Friendships and other social relationships can take many forms across many contexts. Some evidence suggests that autistic adults prefer to interact with other autistic adults (Milton & Sims, 2016; Watts et al., 2024). This could be reflective of the ‘double empathy problem,’ where autistic and non-autistic individuals experience a bidirectional mismatch in communication and understanding, making cross-group social interactions more difficult and prone to misunderstandings (Milton, 2012). Additionally, some autistic adults express that they have no interest in having friends at all, highlighting the heterogeneity of the autistic experiences and the importance of avoiding making generalizations regarding social preferences (McConachie et al., 2020). It is important to recognize that autistic adults may differ in the types, intensity, and amount of social interaction they find meaningful and fulfilling. In line with this idea, a study by Chan et al. (2022) found that autistic adults engaged in social participation in a broad range of different settings including facilitating connections within their own neighborhoods, common interest groups such as in-person group game nights based on shared interests (e.g., Dungeons and Dragons, playing cards, board games, etc.) or faith-based communities, or online via social media apps such as Discord or Facebook. In the same study, autistic adults identified several strategies they found effective to increase social interactions including practicing social skills in safe places like work or volunteering, using their pets to facilitate social interactions, attending

autism-specific support groups or camps to meet other autistic adults seeking social connections, and using online platforms to find social activities in their community where they can meet people with similar interests (Chan et al., 2022).

Autistic adults report a similar amount of interest in romantic relationships as non-autistic adults but report few opportunities to meet potential romantic partners and shorter relationship duration (Hancock et al., 2019). One study by Yew et al. (2023) evaluated the factors that influence relationship satisfaction for autistic adults and found that perceived partner responsiveness – the degree of support, validation, and acceptance one receives from their partner – was a significant predictor of relationship satisfaction, emphasizing the role of empathy and encouragement in successful long-term romantic relationships. Conversely, challenges with social skills have been associated with more difficulty in both initiating and maintaining romantic relationships for autistic adults (Yew et al., 2021).

Priorities for future research regarding social connectedness in autistic adults should include further investigation of experiences in social connection across the lifespan. Additionally, effort should be made to determine how best to measure factors like loneliness and relationship outcomes in samples of autistic adults (Umagami et al., 2022). Future research could also consider how interpersonal and romantic relationships are affected by big life changes associated with aging (e.g., retirement, menopause, or death of a parent) and could outline how autistic individuals and their friends/partners can best navigate these events. Finally, research on romantic relationships for autistic adults is limited, especially for those with intersecting identities including LGBTQ+ individuals and autistic adults with co-occurring intellectual disability, future research should strive to close these gaps (Ciric et al., 2025; Yew et al., 2021).

Employment, Retirement, and Housing

Security of employment has been associated with QoL in autistic adults (Stewart & Happé, 2025). Concerningly, rates of unemployment or underemployment have been demonstrated across multiple studies to be quite high (Ohl et al., 2017; Roux et al., 2013; Taylor et al., 2015) – with autistic women in one study found to be significantly less likely than their male counterparts to maintain employment over time (Taylor et al., 2015). Despite this, autistic adults have many unique strengths that can help in the workplace. In a study by Cope & Remington (2022), a sample of autistic adults identified their own employment-related strengths, which included cognitive advantages such as attention to detail and pattern recognition, efficiency and ability to work independently, personal qualities such as honesty and dedication, and their diverse and ability to draw on personal experiences. Relatedly, another study examining the factors affecting job satisfaction amongst autistic adults identified both social support in the workplace (e.g., encouragement and acceptance from coworkers and supervisors) and person-environment fit (e.g., choosing a job that aligns with one's interests) as important factors related to job satisfaction (LaPoint, 2024). Finally, a study by Ohl et al. (2017) suggested that employment outcomes may be shaped by a disclosure of autism diagnosis, level of education, and workplace accessibility/supports.

There is a very limited amount of research surrounding experiences of retirement for autistic adults, with only two retirement studies identified by the current review. One study by Davies et al. (2024), interviewed older autistic adults regarding their experiences with retirement. Some individuals reported that their autistic traits, such as attention to detail, made planning for retirement seem easy, while others indicated that their experiences of navigating retirement planning were rife with administrative challenges and burnout. Respondents in this study also described retirement as a period of significant personal changes to routine, identity, and social

connections (Davies et al., 2024). A second study by Kowalczyk et al. (2026) demonstrated similar results, with autistic adults experiencing varying degrees of preparedness for retirement but found no differences between autistic and non-autistic adults regarding expected or actual age of retirement.

Research regarding housing and residential care options for autistic adults is similarly lacking. In many cases, transitioning to residential care can be a long process that may incur both physical and mental health challenges for autistic adults and their families (Brotman et al., 2021). An important study by Crompton et al. (2020) identified priorities for improving residential care for autistic adults. These priorities included better autism-informed training for staff members, improved sensory accommodations – personalized to each individual (e.g., natural lighting and quiet environments), and creating community and involvement within residential care settings.

Several key directions for future research were identified across studies. Firstly, future research should continue to evaluate employment-supports for autistic adults, particularly for women or gender diverse individuals who may encounter more or different, barriers to employment-inclusion (Nicholas & Klag, 2020). One study identified that an interesting future research question could be to evaluate how autistic traits (e.g., impairments to executive functioning) relate to access to employment for autistic adults (Cope & Remington, 2022). Additionally, research regarding retirement experiences for autistic adults is extremely limited, leaving a significant gap in the literature that needs to be addressed. Lastly, special attention should be paid to evaluating residential care options for autistic adults and improving experiences and support in group living arrangements with direct guidance from the autistic community.

Broad Gaps and Future Directions

Despite an increase in research surrounding autism and aging, the existing evidence base remains relatively small with significant gaps to be addressed. While some important priorities for each domain of autistic aging were indicated in their distinct section of this report, the broader, overarching directions for research are identified here. Much of the existing literature in this area relies on cross-sectional design or wide age ranges, making it tricky to disentangle actual age-related changes from cohort effects. Due to this, the most consistent recommendation for future research across many of the studies included in this brief review is the need for larger-scale longitudinal studies that follow autistic individuals throughout their lifespan (Bessé et al., 2025; Edelson et al., 2020; Kassee et al., 2020; Klein & Kinger, 2024; Stewart et al., 2026a; Stringfellow et al., 2025; Wright et al., 2016). Following this idea, future research should make an effort to include – or focus on – older age ranges (e.g., 60+). Additionally, limitations in diagnostic criteria and tools were also identified. Existing diagnostic criteria/tools were developed using younger populations, meaning they may not effectively capture the presentation of autism in older adults (Amanullah et al., 2020). Furthermore, more research is needed into what constitutes “successful” aging from the perspective of autistic adults and what factors can influence these outcomes, particularly in populations with intersecting identities including co-occurring ID (Hwang et al., 2017). In fact, another of the most commonly occurring recommendations for future research found in this review was the need to explore the role of intersecting identities in aging, as most studies did not address differences in gender and sexuality, diverse racial, ethnic, cultural, and socioeconomic backgrounds, or variation in levels of support needs and communication differences (i.e., individuals that are non-speaking).

Importantly, the current project identified a notable barrier between the autism community and the accessibility of the research meant to support it. Survey respondents

emphasized a need for research findings to be communicated in ways that are accessible, readily available (i.e., no prohibitive costs), and *practical* indicating a preference for resources that can be readily applied to everyday life. Therefore, increasing emphasis should be placed on knowledge mobilization and open science practices where ethically plausible. This can include publishing preprints or open-access manuscripts (if funding allows), providing plain-language summaries, and disseminating resources through community organizations or practical resources. For example, AIDE Canada provides free, peer-reviewed sources including articles, toolkits, and webinars for autistic adults and caregivers that tackle a wide range of topics (see <https://aidecanada.ca/>).

Another consideration of great importance is building inclusive and community-based research with autistic adults and the autism community. This should extend farther than one-time consultations or inclusion only as study participants. Community members have expressed frustration surrounding narrow and deficit-focused understandings of autism that fail to consider broader, environmental contexts and the experiences of autistic people (den Houting, 2019; Haar et al., 2024). Additionally, they have emphasized a need for the incorporation of autistic voices at every stage of research. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE, <https://aaspire.org/>) have developed practice-based guidelines to promote the inclusion of autistic individuals in research both as members of research teams and as study participants. Recommendations for the inclusion of autistic adults as co-researchers center around ideas such as experiential knowledge as valuable knowledge, maintaining transparency regarding partnership goals, clearly defining roles and expectations, developing processes to optimize communication for effective collaboration, emphasizing building and maintaining trust, collaborating for successful knowledge mobilization, encouraging capacity building, and fairly

compensating partners for their expertise (Nicolaidis et al., 2019). Within this project, the next phase will focus on sharing the findings from the community survey and literature review through diverse knowledge-sharing formats, including this report, an infographic, and presentation (in-person and online). These findings will be shared with community members to gather their perspectives and insights, which will help shape future directions for developing an inclusive, community-based research program focused on aging and autism.

Conclusion

The present report is a part of an ongoing effort to expand knowledge and resources surrounding autism and aging. Here, we integrate perspectives from the autism community with a review of the current landscape of research in this area to demonstrate the progress that has been made, and the gaps that still remain. It is our hope that as this literature base develops, researchers will continue to recognize the importance of centering autistic voices and engage in meaningful collaboration with the autism community so that the lived experiences of autistic adults can help shape the research priorities and knowledge dissemination practices of the field.

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