

AGING ON THE SPECTRUM: PERCEPTIONS OF AGING IN PLACE IN AUTISTIC
ADULTS AND THEIR CAREGIVERS

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requirements for the degree of Master of Science in Occupational Therapy

by

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Abstract

Introduction: Autism presents individuals with unique challenges that may hinder their capacity to participate in daily tasks. As autistic adults transition into older adulthood, they face new challenges related to aging. Despite an increase in prevalence, there continues to be a lack of research on autism and aging. Our study focuses on the perspectives and lived experiences of autistic adults and autistic adult caregivers regarding their ability to age in place. This qualitative study utilized an online global survey to understand the enablers and barriers of aging in place among our participants.

Objective: The purpose of this qualitative research study is to investigate and gain insight into the lived experiences and perceptions of aging in place to identify potential contributors and barriers, among a global sample of autistic adults and autistic adult caregivers.

Methods: Participants were recruited through a flyer posted on OT4OT and its sister groups and word of mouth by our primary advisor's network. Our final sample size consisted of 80 participants: 78 autistic adults (54 formally diagnosed & 24 who self-identify) and 2 caregivers. The gender distribution was 44 females, 7 males (2 reported males from the caregiver sample), 25 non-binary, 2 transgender, and 2 who responded other. Participants participated through an anonymous online survey followed by the analysis of responses to identify recurring themes and patterns.

Results: Two primary themes were identified: support networks and symptoms of autism on daily functioning. Within the theme of symptoms of autism on daily functioning, two subthemes were prominent: challenges related to sensory sensitivities and executive dysfunction.

Conclusion: Our study suggests that social support networks and symptoms of autism on daily functioning have an impact on the ability to age in place among autistic adults. Our research findings can help the development of occupational therapy interventions and offer important insight to support autistic adults throughout the aging process.

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Aging on the Spectrum: Perceptions of Aging in Place Among Autistic Adults and Their Caregivers

By 2050, the estimated global population of individuals over the age of sixty is projected to be approximately 2.1 billion, reflecting an increased lifespan beyond the age of sixty (World Health Organization, 2022). As a result, research has focused on identifying ways to increase quality of life. There has been a focus on the ability to age in place. Aging in place (AIP) is defined as the ability of an individual to remain in their own home as they get older (National Institute on Aging, 2023). It enables individuals to age within their homes and communities, receiving essential support and care without the need for institutionalization (National Institute on Aging, 2023; Ratnayake et al., 2022). AIP allows older adults to maintain independence and promotes autonomy (National Institute on Aging, 2023). However, this may be difficult for many older adults as they are susceptible to age-related changes and experience a high prevalence of health conditions (National Institute on Aging, 2023). AIP may present a considerable challenge for autistic adults who must navigate typical age-related changes but also face the unique complexities of autism spectrum disorder (ASD).

Approximately one in one hundred children worldwide are diagnosed with ASD (Zeidan et al., 2022). ASD is a developmental disorder characterized by challenges in social communication and repetitive behaviors (Centers for Disease Control and Prevention, 2024b). Symptom severity can vary widely among individuals on the spectrum, resulting in a wide range of unique responses (National Institute of Mental Health, 2024). Autistic adults may encounter challenges in acquiring language abilities, comprehending others, and expressing themselves non-verbally through eye contact,

facial expressions, or gestures (National Institute of Deafness and Other Communication Disorders, 2020). They can often demonstrate difficulty with executive functioning, alternative learning styles, movement patterns, and ways of focusing their attention (Centers for Disease Control and Prevention, 2024a; Wallace et al., 2016). Autistic adults are also known to experience sensory reactivity (MacLennan et al., 2021). According to research, autistic adults are commonly sensory-seeking or sensory-hyperactive (MacLennan et al., 2021). Individuals with sensory hyperactivity perceive sensory input more intensely compared to others, which may be dysregulating, overwhelming, and even painful. Those who are sensory-seeking tend to actively seek sensory input for prolonged periods, finding it stimulating or self-regulating. Although some individuals may find sensory experiences enjoyable, they can be distressing for autistic adults which can impact their quality of life. The symptoms associated with ASD can often hinder the capacity to participate in daily activities including school, work, and other areas of life, thus presenting significant challenges in life (National Institute of Mental Health, 2024; Centers for Disease Control and Prevention, 2024a).

As autistic adults transition into older adulthood, the aging process presents unique challenges that have yet to be comprehensively explored. Limited research has been conducted on the lived experiences of AIP among autistic adults and their caregivers. The purpose of our research study is to investigate and gain insight into the lived experiences and perspectives of AIP among autistic adults and their caregivers. Our qualitative study aims to explore the following research questions:

- What are the lived experiences and perceptions of aging in place among autistic adults and caregivers?

- What factors contribute to and are barriers to aging in place in autistic adults?

Through an examination of the perspectives of autistic adults and their caregivers, this research will provide valuable insights into the contributors to AIP, allowing occupational therapy to pave the way for the development of targeted interventions and accessible resources. Occupational therapy not only focuses on occupations but acknowledges that participation in home and community life supports and maintains health (American Occupational Therapy Association, 2020). This research will guide occupational therapy practitioners to support autistic adults and provide specific interventions, ultimately enhancing their quality of life and promoting their ability to AIP and live within the community. For our thesis and consistency, we will refer to the National Institute on Aging's definition of AIP (National Institute on Aging, 2023).

Literature Review

Our literature review aimed to assess the research gap and identify commonalities in research regarding ASD and AIP. Autism research has primarily focused on the pediatric population and sensory modulation. Despite the increasing awareness of ASD, the transition into adulthood remains stigmatized. Current literature has indicated the factors associated with AIP in neurotypical adults, the impact of social support, caregiver concerns, and challenges experienced by this population. We identified a lack of research on indicators or perceptions of AIP among autistic adults and their caregivers.

Physical and Mental Health Challenges

A recurring theme that emerged in our literature review concerned the physical and mental health challenges experienced by autistic adults. Several studies have indicated that autistic adults are more likely to experience a prevalence of physical and mental health conditions (Liu et al., 2023; Mason et al., 2021; Roestorf et al., 2022; Uljarević et al. 2019). Liu et al. (2023) investigated the association between autism and health conditions, revealing that older autistic adults above the age of 45 exhibit an increased risk for both age-related physical conditions and physical injuries compared to non-autistic adults. These conditions included cerebrovascular disease, heart failure, and visual and hearing changes, among others. In a complementary study, Roestorf et al. (2022) aimed to explore the impact of autistic traits and co-occurring health conditions on quality of life. The study revealed that difficulties in mental health and having a higher number of autistic traits were predictors of poor quality of life, affecting daily tasks such as social relationships, employment, and housework. Mason et al. (2021) explored the association between autistic traits and markers of aging and found that a higher number of autistic traits were associated with poorer health outcomes and a faster pace of aging. Uljarević et al. (2019) highlighted a higher prevalence of anxiety and depression across the autistic population compared to the general population. These studies demonstrate the challenges encountered by autistic adults, revealing a higher incidence of physical and mental health conditions. The implications for aging are significant, suggesting concerns about their ability to age in place, given the increased risk and impact on daily life.

Social Support

Another theme we identified was social support. Several studies have addressed social support and quality of life, focusing on autistic and neurotypical adults. A study by Charlton et al. (2023) focused on social support and its impact on quality of life among middle-aged and older autistic adults. Higher levels of quality of life were found to be associated with greater social support, while lower social interaction skills were linked to a decline in quality of life. A study comparing typically developed adults and older autistic adults revealed that autistic adults tend to experience a lower quality of life (Atherton et al., 2021). Mason et al. (2018) offered a different perspective, finding that receiving social support and being in a relationship were positive predictors of quality of life. This study also identified age as a negative predictor of quality of life, suggesting a complex relationship between age and well-being. Uljarević et al. (2019) emphasized the significance of social support by revealing that impairment in social functioning among autistic adults contributes to the development of anxiety and depressive characteristics, leading to increased isolation and subsequent anxiety. These findings emphasize the impact of social support on the quality of life of autistic adults, suggesting that social support systems are crucial for improving their overall well-being. The current evidence indicates that social support and social interactions may be predictors of quality of life and AIP among autistic adults.

Bosch-Farré et al. (2020) conducted a qualitative study examining factors influencing AIP in research involving neurotypical older adults. Participants highlighted the importance of healthy aging for their quality of life, with emotional and social factors being identified as crucial components. Living in a community and actively participating

in social support services was identified as essential for reducing loneliness and fostering a sense of belonging, facilitating a person's ability to age in place (Bosch-Farré et al. (2020). Individuals living in urban environments identified negative opinions and difficulties regarding the aging process (Bosch-Farré et al., 2020). Carr and Weir (2016) further reinforced the importance of a support network in successful aging, emphasizing its role in providing assistance, care, and vigilance for older adults. Tkatch et al. (2017) reiterated this, identifying social support as a key indicator of maintaining health and aging successfully. These studies collectively demonstrated the importance of social connections and strong support networks in enhancing quality of life and promoting AIP. This reinforces that successful aging and AIP are not solely determined by physical health but are significantly influenced by social connections and the establishment of strong support networks. While social support emerges as a crucial enabler to facilitate AIP, it is important to recognize that this may pose a unique challenge for autistic adults as one of the primary symptoms of ASD involves challenges with social communication and social interactions (Centers for Disease Control and Prevention, 2024b).

Caregiver Concerns: Lack of Services and Future Care

A theme we identified among caregivers was concerns with a lack of services and future care. According to Marsack-Topolewski (2019), quality of life is known to be higher and more positive when caregivers and autistic adults receive formal and informal support networks. However, evidence demonstrates that caregivers and parents of autistic adults have a difficult time finding adequate, affordable, and accommodating services (Marsack-Topolewski, 2019). In a qualitative study conducted by Shivers et al. (2019), the needs of autistic adults and their family caregivers were assessed, demonstrating a

high percentage of unmet service needs for autistic adults. Findings indicated that although autistic adults receive basic health needs, there are high levels of unmet services for autistic adults and their families. Caregivers reported concerns over the lack of services for autistic adults as they age. In another qualitative study by Oti-Boadi et al. (2019), the researchers identified the lived experiences of parents who had autistic adult children. The results revealed that parents have feelings of uncertainty and anxiety related to their adult children's independence and self-care, and demonstrated that several parents lacked adequate plans for their children's future. These studies collectively emphasize and demonstrate the need to explore the lived experiences of caregivers to identify potential barriers and enablers to AIP in autistic adults.

Aging in Place in Neurotypicals

The final theme we recognized pertained to the concept of AIP among neurotypical adults, as limited research has been conducted on the autistic population. As the autistic population undergoes the aging process, AIP has gained much attention in discussions surrounding the well-being and quality of life of older adults. In a cross-sectional study that examined 9,930 adults living in Korea, AIP was higher in those with higher access to health care needs and in community care (Cho & Kwon, 2023). Healthier lifestyles, owning a home, and increased residential satisfaction were indicators of increasing AIP (Cho & Kwon, 2023). Ho et al. (2023) sought to examine and identify activities of social participation that contributed to successful aging. Individuals who participated in group activities, volunteer or charity work, recreational activities, or educational or cultural activities indicated higher levels of successful aging compared to others who did not participate in these activities. This highlighted the positive correlation

between recreational activities and successful aging. It also signified the importance of the well-being of older adults by mitigating social isolation and enhancing their sense of belonging within the community. In a study conducted by Asquith-Heinz et al. (2022), components of successful aging were examined in adult Alaskan Natives. The study identified critical aspects such as physical health, spirituality, the native way of life, emotional well-being, and family as contributors to successful aging. It emphasized the centralization of family as an important contributor, challenging Western beliefs of individualism. Additionally, critical aspects such as culture, spirituality, and family engagement were contributing factors to successful aging (Asquith-Heinz et al., 2022). Recognizing the importance of these cultural and familial elements, it becomes evident that tailored interventions are crucial in supporting aging in place. Another study revealed that a two-visit occupational therapy home modification program can be instrumental in supporting successful AIP for older adults (Grasso et al., 2023). This occupational therapy program highlights the role of occupational therapy in adapting home environments to meet the specific needs of older adults, facilitating their ability to age in place. While these studies emphasize facilitators that contribute to AIP in neurotypical older adults, this poses a concern for AIP among the autistic population.

Research Literature Gaps

According to the literature, limited research has been conducted on factors indicating AIP among autistic adults. While various sources discuss physical and mental health challenges, the impacts of social support, caregivers' concern with lack of services and future care, and AIP in neurotypical adults, limited research has been conducted on the perceptions of AIP among autistic adults. Our study aims to address the gap in the

existing literature by exploring the unique challenges, barriers, and facilitators associated with AIP among this population.

AIP is relevant as it allows older adults to preserve their autonomy, maintain their independence, and enhance their overall well-being. Studies have provided valuable insights into the challenges faced by this population. Mason et al.'s (2018) research demonstrates that autistic adults are noted to experience a diminished quality of life. Existing literature neglects the impact of aging on autistic adults and its effects on quality of life. Given the limited research, it is crucial to explore distinct factors that influence AIP. Our study aims to explore the perceptions and lived experiences of autistic adults and their caregivers on AIP, identifying specific enablers and barriers unique to this population. This research will offer valuable information on how to support older autistic adults and guide the development of occupational therapy interventions based on their specific needs. As future occupational therapists, this is essential to gain a comprehensive understanding of this population.

Theoretical Framework

The Person-Environment-Occupation-Performance (PEOP) model serves as the foundational framework for our study of the lived experiences of aging among autistic adults. This model is employed within the domain of occupational therapy and addresses an extensive range of environments and demographics (Cole & Tufano, 2020). The PEOP model emphasizes the intricate connections between an individual's inherent attributes, their environmental context, and their participation in various activities (Cole & Tufano, 2020). The outcome of these interplays, known as occupational performance, is articulated as the achievement of meaningful activities, tasks, and roles resulting from

interactions between individuals and their environment, which provides essential insight into the AIP experience of autistic adults (Cole & Tufano, 2020).

The occupational therapy discipline, recognized for its client-centered approach, advocates for a comprehensive assessment of the client that fully captures the various dimensions of their lives (Cole & Tufano, 2020). Within the PEOP framework, the 'Person' component considers autistic adults, highlighting the various roles and responsibilities they carry. Through a lens that encompasses psychological, cognitive, neurobehavioral, physical, and spiritual aspects, a thorough understanding of the quality of life and its challenges for autistic individuals emerges, often indicating greater difficulties than in the general population (Mason et al., 2018). Our study will extend this personal assessment to include how participants perceive their ability to engage in activities and their independence, by examining various relevant aspects.

In the 'Environment' facet, the PEOP model delves into the multifaceted contexts in which individuals participate, ranging from their familiar personal spaces to the broader societal structures influencing their lives (Cole & Tufano, 2020). It states that the environment significantly shapes one's behaviors and decisions, thereby affecting their capacity to age gracefully and independently (Bosch-Farré et al., 2020; Cole & Tufano, 2020). The online surveys in our study will collect data from participants about their physical, social, and cultural surroundings, including available healthcare resources, and how these factors support or challenge their ability to live autonomously.

Regarding 'Occupation,' the PEOP model considers the spectrum of daily tasks, leisure pursuits, and roles within the community that occupy autistic adults' time (Cole & Tufano, 2020). Research emphasizes the importance of social participation and leisure in

suggesting that the occupational experiences of autistic adults may differ and pose distinct challenges (Cole & Tufano, 2020; Ho et al., 2023). In our study, we use survey questions to capture how autistic adults and their caregivers engage with these tasks. We also examine the impact on their sense of fulfillment, quality of life as they age, and ability to age in place.

Finally, 'Performance,' as defined in the PEOP model, assesses the capability of autistic adults and caregivers to address daily life challenges and find satisfaction in their activities (Cole & Tufano, 2020). Given the heightened health risks and mental health concerns, such as tendencies towards self-harm and suicide among autistic adults (Liu et al., 2023), access to healthcare and proper support (Cole & Tufano, 2020) significantly improves performance. By incorporating questions about the support mechanisms in place, our study aims to shed light on the occupational performance of autistic adults as they age and develop insights for improving such performance.

The use of the PEOP model in our research involves combining various elements that impact AIP, such as social support networks, physical health, and personal values like spiritual beliefs and cultural practices. Questions within the survey will attempt to identify enablers and barriers, aiding in piecing together the complex experiences of autistic adults and their caregivers. To identify effective strategies, gauge environmental responsiveness, and understand occupational engagement, our study's findings will help inform interventions and support structures to enhance the well-being and aging process of the autistic adult community (Cole & Tufano, 2020).

Methodology

Our study is a pilot qualitative research study that employs an ethnographic research approach. It used an anonymous online survey to gather the perceptions and lived experiences of autistic adults and their caregivers on AIP. The research aimed to uncover the insights and challenges related to how autistic adults perceive and navigate the aging process. All participants had to meet the following criteria to participate: an individual aged 25 and older who has a formal diagnosis of ASD or self-identifies as autistic or is a formal or informal caregiver of an autistic adult who is 18 years or older. The decision to include individuals who are 25 years of age is informed by the aim to capture a cohort of adults who have undergone significant life transitions and independent adult life, providing a comprehensive perspective on AIP. For participants who are caregivers, we utilized specific definitions to identify the two groups. Informal caregivers are described as individuals who provide care who are unpaid including family members, friends, or neighbors (Centers for Disease Control and Prevention, 2021). Formal caregivers are paid employees or volunteers who provide care in a formal setting (Centers for Disease Control and Prevention, 2021). To encompass a wider demographic of autistic adults, we decided to include autistic adults with co-occurring conditions. The exclusion criteria consisted of autistic adults who received an Autism Spectrum Quotient (AQ)-28 score below 14 in the screening process.

Prior to data collection, a draft survey was created, and the principal and co-investigators reviewed it from their perspectives to ensure it met the participants' needs. We also invited another autistic occupational therapist to independently review the draft survey. The recruitment source for our study's participants occurred through Facebook

groups including OT4OT and its network of over 70 sister groups. We posted the flyer on the main OT4OT Facebook group and encouraged members to share it within their affiliated sister groups. Facebook participants were invited to participate in the study through a flyer posted online. Since the majority of the members in these groups are occupational therapy students and practitioners, we encouraged them to share the flyer with autistic individuals and their caregivers within their networks. The flyer included a QR code that provided direct access to the consent form followed by the survey. The 25-minute survey was completed online using Google Forms. It consisted of a preliminary screening, demographic questions, and two free-response questions to gather in-depth insight into the lived experiences and perceptions of AIP. Once surveys were completed, their responses were analyzed using a thematic analysis using Dedoose software (<https://www.dedoose.com>). This software helped to identify common themes and patterns in the research data. In addition, demographic information provided by participants was analyzed using Jamovi software (<https://www.jamovi.org>) to generate descriptive statistics. For demographic data, tables and graphs were utilized to display an overview of the distribution of the data.

As part of the study design, we incorporated a brief screening process within the survey instrument. The screening tool implemented is the AQ-28. The AQ is “a 50-item self-report questionnaire that assesses autistic traits in individuals with normal intelligence” (Hoekstra et al., 2010). However, for our study, we used the AQ-28 which is a shorter version of the AQ that is less demanding to complete, which includes 28 items (Hoekstra et al., 2010). It included a series of statements about the participant’s behaviors and experiences. These responses generated a score indicating the level of

autistic traits present in each participant. All data from participants with a score below 14 was omitted. This portion did not apply to the caregiver participants as they did not undergo the screening process. The subsequent section included questions about the participants' demographics, including age, gender, level of education, continent of residence, and employment status. Our study also incorporated the Lawton Instrumental Activities of Daily Living Scale (IADL) under the demographic section. This instrument was used to collect data on independent living skills necessary for functioning within the community (American Psychological Association, 2020). The survey included two free-response questions to identify factors, challenges, and emerging themes from the AIP experiences of autistic adults and caregivers of autistic adults. The AQ-28 was used in the study without the need for permission, as it is a shortened version of the widely available and freely accessible AQ-50. Permission was not required to use the Lawton IADL scale, as it is freely available according to the Gerontological Society of America's copyright.

Thematic analysis was used to identify recurring themes and patterns for the online survey responses. This methodology was well-suited to investigate the lived experiences and perceptions of AIP among autistic adults and caregivers of autistic adults. Ensuring our participants' privacy and confidentiality was paramount, thus our collaborators received a summary of our findings without identifiable information. As a part of a pilot study, students involved in future phases of this research project will have access to the summary of the results as well. Since we collected email addresses for participants who wish to participate in future follow-up interviews, our thesis advisor, collaborators, and future research groups will have access to such email addresses. The data will securely be destroyed three years after cessation of the study. Our study is

designed to lay the groundwork for future research studies in this field and area of interest. Refer to Appendix B for the online survey guide.

Ethical and Legal Considerations

Before the start of the data collection process, we met with our principal investigator Dr. Wong, and co-investigators Dr. Foley, Dr. Kornblau, Dr. Mills, and Dr. Coxon to develop the first draft of our online survey. We received feedback from an external source from our principal investigator to corroborate that our consent form and survey were designed for this population. To ensure that there was stakeholder input, we reconvened with our principal investigator who helped us review our online survey before developing the finalized draft. As our study used a small sample size obtained from an online survey pool, there are no conflicts of interest. Our data collection process does not involve any personal acquaintances because random participants from our online survey pool can complete the survey anonymously, without any influence from our research team or the existence of any bias towards specific participants. Our principal investigator's social media presence did not impact our study as the participants' selection process was anonymous. Our research team maintained transparency and objectivity throughout the research process. To ensure ethical research conduct, we drafted voluntary and informed consent forms that were approved by the Stanbridge University Institutional Review Board. Participants were made aware that all data would be properly collected, stored, and secured on Google Drive and it would be destroyed 3 years after the cessation of our study. This methodology was selected by the research team to minimize potential biases.

Additional ethical and legal factors we took into consideration involved the risks faced by our participants and the steps we took to mitigate these risks to ensure their safety. Participants involved in this study were exposed to potential minimal risks to their psychological and physical well-being. Participants were at a minimal physical risk including fatigue or eye strain from staring at a screen for an extended amount of time while participating in our study due to the online nature of this survey taken on an electronic device. We minimized this risk by allowing participants to complete the survey at their own pace and return to the survey at a later point in time to recuperate and prevent eye pain. There was also a minimal psychological risk, which included distress when answering questions on the survey. Due to the online nature of Google Forms, there was a minimal risk of data breach, but we could not eliminate this risk. We minimized these risks by making the data anonymous and not asking for personal identifiers. In addition, all data was stored on a password-protected account and computer. We also ensured our survey on Google Forms had a safeguard against bots with a captcha question for human verification. All participants were provided the option to skip a question or withdraw from the survey at any time if they felt uncomfortable at any point during the study. This option aimed to alleviate any pressure participants may feel when answering questions, ultimately ensuring their comfort throughout the online survey process.

Our study adhered to the agencies enforcing legal and ethical guidelines, such as the Stanbridge University Institutional Review Board and the Office for Human Research who maintain data access. While our findings may be disseminated through publications or presentations, all results will be presented using de-identified data only. Our

collaborators in our study did not interact directly with participants or access raw data, including the survey transcriptions. The research team had access to participants' de-identified data for analysis, which will be retained until June 2024 for ongoing study purposes, with final data retention ending in April 2027. All personal information was removed or coded to meet current scientific standards and methods, ensuring that no one could identify participants from the shared information. Nevertheless, our research team was committed to upholding privacy to the highest attainable degree.

Results

A total of 124 participants (119 autistic adults and five caregivers) participated in our survey. Only 80 participants were included in the final analysis. The data of 44 participants was excluded for the following reasons: four autistic adults did not meet the age requirement, six autistic adults did not qualify according to the AQ-28 score, and 34 participants did not complete the survey. The participants consisted of 54 formally diagnosed autistic adults, 24 autistic adults who self-identified as autistic, and two informal caregivers. The age of the participants ranged from 25 to 72, with a median age of 34. Regarding gender representation, 44 participants were female, seven were male (two reported males from the caregiver sample), two were transgender, 25 were non-binary, and two responded other, as shown in Figure 1. Participants from different continents were included to gather a wider range of perspectives, with 51 participants from North America, 22 from Europe, and seven from Australia/Oceania as shown in Figure 2. In terms of ethnicity distribution, the participants consisted of the following: 66 White/Caucasian, six Hispanic or Latino, two Black or African American, two Asian, and one American Indian or Alaska Native, as demonstrated in Figure 3. Additional

demographic data was also collected. This included participant's education levels, employment status, and the presence of other medical conditions. The educational backgrounds of participants varied widely, providing information regarding their academic experiences as shown in Figure 4. The level of education of the sample was as follows: one participant with less than high school education, eight participants with high school education, 19 participants with some college but no degree, eight participants with an associate's degree, 25 participants with a bachelor's degree, 13 participants with a master's degree, five participants with a doctoral degree, and one participant who reported other. Employment status was recorded to capture the professional situations of each participant, illustrated in Figure 5. The employment status of the participants varied and included the following: 35 participants were full-time, 16 participants were part-time, eight participants were unemployed, three participants were self-employed, two participants were retired, four participants were students, 10 participants were unable to work, and two participants reported other. For our study, full-time employment was defined as working 30 hours or more per week and part-time was less than 30 hours per week. Results also indicated that 79 of the participants reported having co-occurring conditions. Information on these medical conditions was gathered to understand the broader health context of the participants as illustrated in Figure 6. Demographic data was collected using the Lawton IADL scale to gather information on independent living skills as shown in Table 1.

Following demographic data collection, our study identified two primary themes: support networks, and the symptoms of autism on daily functioning. The theme of support networks emerged prominently in the data, reflecting the crucial role of familial,

social, and professional support systems. Participants frequently discussed the importance of having support from family members, partners, and friends in managing daily tasks, which facilitated their ability to AIP. For example, participant 5 shared, “I’m autistic, I don’t drive so I depend on my family whenever I need to go to work or to a certain place. They support me in all I do and even though I am sure I frustrate them because I don’t drive, they don’t hesitate to try to help me.” Another participant, number 26, noted the impact of support on their quality of life and stated, “I don’t think I’ll ever live alone, for personal preference and safety reasons. I don’t really need supervision, I have low support needs, but things like cooking, cleaning, laundry, feeding our dog, etc., would really hinder me. I think I could manage living alone if I tried really hard, but it would affect my quality of life and really burn me out.” In contrast, other participants discussed the lack of support available to autistic adults. For example, participant 45 stated, “I do think that it might be helpful to have more formal/professional help with this too but that hasn’t been an option so far.” Participant 47 mentioned, “I have not been able to maintain employment for more than a couple of years (and struggled at that), so even though I haven’t *required* assistance does not mean I would not benefit from it.” These quotes highlight the struggles many autistic adults face due to the lack of available support, which acts as a barrier to their ability to AIP. Without these supports, many participants expressed that they would struggle to manage their daily lives and maintain their current living situations. This emphasizes the importance of support networks in facilitating the ability of autistic adults to live independently.

The symptoms of autism on daily functioning was another major theme that emerged from the data. Within this theme, two subthemes were prominent: challenges

related to sensory sensitivities and executive dysfunction. Participants frequently mentioned how these difficulties affected their ability to perform daily occupations including IADL and work. Participant 57 explained, “As I’ve gotten older, overstimulation has become more of an issue. I am ‘high functioning’ but even small sounds within the last year can trigger a physiological response or anxiety. I’ve also found it increasingly more draining to go outside for overstimulation reasons.” Participant 67 shared, “I still feel like the whole adulting doesn't work out really well for me. While if I am forced I can do things. I have several meltdowns during tasks that require contact with icky textures (washing up, doing the dishes, etc.) and while I can drive, have a license I am afraid of doing so.” Additionally, participant 18 described the impact of sensory sensitivities on their ability to engage in the community: “...I feel like I can't go anywhere sometimes. I tried to go out to eat for our anniversary and went to six different places and couldn't even stay at the tables for any of the places. Tried to go to a movie theater and I only made it fifteen minutes into the movie before leaving in tears. I get raging migraines from the lights and perfumes at church. Nowhere feels safe. Nowhere meets my access needs. Every trip out of the house is a huge deal unless I'm out in nature...” This illustrates how sensory sensitivities related to ASD can impact daily functioning and independence.

Executive dysfunction emerged as a prominent subtheme under the primary theme of symptoms of autism and daily functioning. Participants described the impact of executive function on daily tasks. Participant 56 shared, “I find it very difficult to maintain my home with the hours I am forced to work in order to afford rent, but maintaining things would be very difficult even with normal working hours, as I struggle

with executive dysfunction and also find it difficult to switch tasks, as I tend to get absorbed in activities. This also makes meals difficult, as I will often forget to eat, and then preparing a meal can take me far too long to do. I will usually only eat one meal per day if that.” Participant 11 also shared, “My spouse supports me in aiding my working memory...If something happened to them, it would be a significantly challenging adjustment.” Participants also reflected on how these difficulties manifest in the workplace. Participant 60 shared their internal struggle, stating, “...I guess that's why I'm having a lot of conflicting thoughts about trying to find more work. I've always been criticized for being slower than my fellow employees at every job I've worked in the past. I learn slower and I move slower and I'm more meticulous about details and I can't make myself be any other way. My performance at this point would probably be even slower.” Financial independence emerged as a critical concern among participants, with executive dysfunction significantly hindering their ability to secure stable employment. Participant 10 reflected on their reliance on parental support, stating, “Based on my current living situation, I am working a part-time minimum wage job and have never been financially independent. I have to rely on my parents to take care of my finances. I find it hard to find a good job because of my executive dysfunction. The support that I get is from my parents.” In summary, these perspectives demonstrate the significant challenges in managing daily tasks impacting their ability to age in place and overall quality of life.

Discussion

The findings of our study illustrate the relationship between autism and the ability to AIP. As the global population ages, understanding the unique challenges faced by autistic adults becomes increasingly important for maintaining their independence and

autonomy within their homes and communities. The results from the data revealed the role of support networks in facilitating AIP among autistic adults. Participants emphasized the importance of support systems in managing daily tasks and promoting independence. The lack of available support services was identified as a significant barrier to AIP, demonstrating the need to provide appropriate resources and assistance to autistic adults. The findings highlight the influence of autism symptoms on daily functioning, emphasizing the significance of sensory sensitivities and executive dysfunction. Autistic adults described challenges related to sensory sensitivity, which often led to difficulties navigating their environment, participating within the community, and engaging in daily activities. Executive dysfunction was identified as a barrier to independent living. Participants reported struggles with maintaining their homes, preparing meals, and managing finances which demonstrates the impact of executive dysfunction on various aspects of life.

As outlined by the American Occupational Therapy Association (2020), the scope of occupational therapy goes beyond enhancing independence in activities of daily living but also acknowledges the role of community life in sustaining overall health and well-being. Our findings demonstrate that occupational therapy practitioners can play a crucial role in supporting autistic adults by maximizing their independence and improving their health, and overall quality of life. Specific interventions targeting sensory sensitivities, executive dysfunction, and social skills can empower autistic adults to engage in meaningful activities, navigate their environment more effectively, and facilitate their ability to AIP. It is important to consider situations where autistic adults may require medical care at home. Occupational therapy practitioners can advocate and provide

appropriate referrals and resources to ensure that these individuals have access to the necessary services. By serving as a resource, occupational therapy practitioners can help autistic adults attain the medical care and support they need to maintain their health and independence at home. Occupational therapy practitioners can advocate for the development of accessible support services and employment opportunities tailored to the needs of autistic adults. Conversely, for those who are not capable of working, occupational therapy practitioners can implement strategies to support AIP in their surroundings. Occupational therapy can promote autonomy and enhance the quality of life of autistic adults within their homes and communities by addressing their unique needs.

Limitations

It is important to acknowledge the limitations of this study. The first limitation was our study's sample size was small, which may have impacted the generalizability of our findings to the broader population of autistic adults. The small sample size was due to several factors: participants omitted due to our exclusion criteria, those who did not answer open-ended questions of the survey, and those who dropped out of the study. Recruiting participants from an online social media platform (Facebook) may have resulted in a sample that may not be representative of the entire autistic adult population. The sample size of participants who were caregivers was small which may not provide a representative view. The second limitation of our study was that we relied on self-reported data which may have introduced biases and errors. Participants may have described their experiences based on their perceptions, potentially leading to inaccurate reflections of their actual situations. Participants with more severe autism or other health

conditions may have been less likely to participate in the online survey, leading to selection bias. The third limitation was our research team's occupational therapy background, which may have introduced biases. The open-ended survey questions might have been unclear or confusing to some autistic participants due to the use of occupational therapy jargon. The last limitation was that we relied on each participant's ability to articulate their experiences through open-ended survey questions. This may be challenging for autistic adults who struggle with verbal communication or may not have the capacity to provide detailed information about their experiences. The short data collection period and nature of the online survey may not have captured the full range of experiences and challenges related to AIP.

Our study also offered several benefits. Our online survey design allowed us to provide participants with prepared questions, which can be helpful for individuals who may need structure or support when responding to open-ended questions. Conducting the survey online may have been more comfortable for autistic adults who experience challenges with social communication and may feel uncomfortable during interviews. To further reduce dropout rates, our methodology implemented anonymous data collection and allowed participants ample time to save and return to their survey at a different time. Our study included a large sample size of autistic adults. These strategies helped mitigate potential limitations and ensure the integrity of the research outcomes.

Conclusion

In summary, our thesis explored the lived experiences and perceptions of AIP among autistic adults and their caregivers. As autistic individuals transition into older adulthood, the aging process presents distinct challenges. A comprehensive review of the

current literature revealed several common themes. Numerous studies indicated a higher prevalence of physical and mental health conditions in autistic adults (Liu et al., 2023; Mason et al., 2021; Roestorf et al., 2022; Uljarević et al. 2019). Social support was found to significantly impact their quality of life and overall well-being. Studies of caregivers of autistic adults suggested a lack of adequate support and planning for the future. Despite the emphasis on factors contributing to AIP in neurotypical adults, limited research has been conducted on the lived experiences of autistic adults. Through a qualitative approach, our study aimed to explore the perceptions and lived experiences of autistic adults and their caregivers on AIP, identifying specific enablers and barriers unique to this population. By identifying these barriers and enablers, our findings can provide valuable information on how to support older autistic adults and guide the development of occupational therapy interventions. Our findings identified two major themes that emerged as important to contributing to or hindering AIP: the significance of support networks and symptoms of autism on daily functioning. The first theme highlighted the dual role of support systems, where needing support was a barrier to independence and self-advocacy, but having access to family or professional support was a key enabler that provided essential resources and accommodations. The second theme, symptoms of autism on daily functioning was a significant barrier to independent living. These findings indicate that occupational therapy can effectively address the unique challenges autistic adults encounter.

According to the American Occupational Therapy Association's "Centennial Vision," our study exemplifies the importance of promoting community engagement in supporting and maintaining health, as well as recognizing the value of occupation in

fostering independence and quality of life (American Occupational Therapy Association, 2007). Occupational therapy can enhance the quality of life and promote autonomy among autistic adults within their homes and communities. Occupational therapy practitioners can address sensory sensitivities, executive dysfunction, and social skills to empower autistic adults to engage in meaningful activities, navigate their environment more effectively, and facilitate their ability to AIP.

By filling a gap in existing literature, our research provided valuable insights for future studies and improved outcomes for autistic adults. Future research should explore the complex interplay between aging and autism using interviews, shedding light on the specific challenges that arise as autistic individuals transition into older adulthood. This understanding can help us better address the unique needs of this population and develop targeted interventions to support them in AIP. Future studies should also be conducted to examine the long-term effects of occupational therapy interventions on the daily lives of autistic adults as they age and to identify potential predictors of successful aging in place. By furthering research into these concerns, we can ensure that autistic adults maintain their independence, autonomy, and quality of life as they age.

References

- American Occupational Therapy Association. (2007). AOTA's centennial vision and executive summary. *The American Journal of Occupational Therapy*, 61(6), 613-614. <https://doi.org/10.5014/ajot.61.6.613>
- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process fourth edition. *The American Journal of Occupational Therapy*, 74(Suppl. 2). 1-87. <https://doi.org/10.5014/ajot.2020.74S2001>
- American Psychological Association. (2020, June). *Instrumental Activities of Daily Living Scale*. <https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/daily-activities>
- Asquith-Heinz, Z., Kim, S., & Lewis, J. P. (2022). Alaska Native successful ageing in Northwest Alaska: How family impacts how one ages in a good way. *International Journal of Circumpolar Health*, 81(1), Article 2147127. <https://doi.org/10.1080/22423982.2022.2147127>
- Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2021). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *Journal of Autism and Developmental Disorders*, 52(8), 3639–3654. <https://doi.org/10.1007/s10803-021-05235-x>
- Bosch-Farré, C., Malagón-Aguilera, M. C., Ballester-Ferrando, D., Bertran-Noguer, C., Bonmatí-Tomás, A., Gelabert-Vilella, S., & Juvinyà-Canal, D. (2020). Healthy ageing in place: Enablers and barriers from the perspective of the elderly. A

- qualitative study. *International Journal of Environmental Research and Public Health*, 17(18), Article 645. <https://doi.org/10.3390/ijerph17186451>
- Carr, K., & Weir, P. L. (2016). A qualitative description of successful aging through different decades of older adulthood. *Aging & Mental Health*, 21(12), 1317–1325. <https://doi.org/10.1080/13607863.2016.1226764>
- Centers for Disease Control and Prevention. (2021, September 16). *Tips for Caregivers*. <https://www.cdc.gov/healthliteracy/developmaterials/audiences/olderadults/tipsfor caregivers.html>
- Centers for Disease Control and Prevention. (2024a, January 25). *Signs and symptoms of autism spectrum disorders*. https://www.cdc.gov/autism/signs-symptoms/?CDC_AAref_Val=https://www.cdc.gov/ncbddd/autism/signs.html
- Centers for Disease Control and Prevention. (2024b, May 14). *About autism spectrum disorder*. https://www.cdc.gov/autism/about/?CDC_AAref_Val=
- Charlton, R. A., McQuaid, G. A., & Wallace, G. L. (2023). Social support and links to quality of life among middle-aged and older autistic adults. *Autism: The International Journal of Research and Practice*, 27(1), 92–104. <https://doi.org/10.1177/13623613221081917>
- Cho, M. S., & Kwon, M. Y. (2023). Factors associated with aging in place among community-dwelling older adults in Korea: Findings from a national survey. *International Journal of Environmental Research and Public Health*, 20(3), Article 2740. <https://doi.org/10.3390/ijerph20032740>
- Cole, M. B., & Tufano, R. (2020). *Applied theories in occupational therapy: A practical approach* (2nd ed.). SLACK Incorporated.

- Grasso, A. Y., Murphy, A., & Abbott-Gaffney, C. (2023). The impact of a two-visit occupational therapy home modification model on low-income older adults. *The Open Journal of Occupational Therapy, 11*(1), Article 7.
<https://doi.org/10.15453/2168-6408.2047>
- Ho, M., Pullenayegum, E., & Fuller-Thomson, E. (2023). Is social participation associated with successful aging among older Canadians? Findings from the Canadian Longitudinal Study on Aging (CLSA). *International Journal of Environmental Research and Public Health, 20*(12), Article 6058.
<https://doi.org/10.3390/ijerph20126058>
- Hoekstra, R. A., Vinkhuyzen, A. A., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., Posthuma, D., & van der Sluis, S. (2010). The construction and validation of an abridged version of the autism-spectrum quotient (AQ-short). *Journal of Autism and Developmental Disorders, 41*(5), 589–596.
<https://doi.org/10.1007/s10803-010-1073-0>
- Liu, S., Larsson, H., Kuja-Halkola, R., Lichtenstein, P., Butwicki, A., & Taylor, M. J. (2023). Age-related physical health of older autistic adults in Sweden: A longitudinal, retrospective, population-based cohort study. *The Lancet Healthy Longevity, 4*(7), 307-315. [https://doi.org/10.1016/s2666-7568\(23\)00067-3](https://doi.org/10.1016/s2666-7568(23)00067-3)
- MacLennan, K., O'Brien, S., & Tavassoli, T. (2021). In our own words: The complex sensory experiences of autistic adults. *Journal of Autism and Developmental Disorders, 52*(7), 3061–3075. <https://doi.org/10.1007/s10803-021-05186-3>
- Marsack-Topolewski, C. N. (2019). A snapshot of social support networks among parental caregivers of adults with autism. *Journal of Autism & Developmental*

- Disorders*, 50(4), 1111–1122. <https://doi.org/10.1007/s10803-019-04285-6>
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, 11(8), 1138–1147. <https://doi.org/10.1002/aur.1965>
- Mason, D., Ronald, A., Ambler, A., Caspi, A., Houts, R., Poulton, R., Ramrakha, S., Wertz, J., Moffitt, T. E., & Happé, F. (2021). Autistic traits are associated with faster pace of aging: Evidence from the Dunedin study at age 45. *Autism Research*, 14(8), 1684–1694. <https://doi.org/10.1002/aur.2534>
- National Institute of Deafness and Other Communication Disorders. (2020, April 13). *Autism spectrum disorder: Communication problems in children*. <https://www.nidcd.nih.gov/health/autism-spectrum-disorder-communication-problems-children>.
- National Institute of Mental Health. (2024, February). *Autism spectrum disorder*. <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd>
- National Institute on Aging. (2023, October 12). *Aging in place: Growing older at home*. <https://www.nia.nih.gov/health/aging-place/aging-place-growing-older-home>
- Oti-Boadi, M., Oppong Asante, K., & Malm, E. K. (2019). The experiences of ageing parents of young adults with autism spectrum disorders (ASD). *Journal of Adult Development*, 27(1), 58–69. <https://doi.org/10.1007/s10804-018-09325-6>
- Ratnayake, M., Lukas, S., Brathwaite, S., Neave, J., & Henry, H. (2022). Aging in place: Are we prepared? *Delaware Journal of Public Health*, 8(3), Article 7. <https://doi.org/10.32481/djph.2022.08.007>

- Roestorf, A., Howlin, P., & Bowler, D. M. (2022, August 23). Ageing and autism: A longitudinal follow-up study of mental health and quality of life in autistic adults. *Frontiers in Psychology, 13*, 1-19. <https://doi.org/10.3389/fpsyg.2022.741213>
- Shivers, C. M., Sonnier-Netto, L., & Lee, G. K. (2019). Needs and experiences of family caregivers of individuals with autism spectrum disorders across the lifespan. *Journal of Policy and Practice in Intellectual Disabilities, 16*(1), 21–29. <https://doi.org/10.1111/jppi.12272>
- Tkatch, R., Musich, S., MacLeod, S., Kraemer, S., Hawkins, K., Wicker, E. R., & Armstrong, D. G. (2017). A qualitative study to examine older adults' perceptions of health: Keys to aging successfully. *Geriatric Nursing, 38*(6), 485–490. <https://doi.org/10.1016/j.gerinurse.2017.02.009>
- Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2019, June 12). Anxiety and depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*(9), 3155–3165. <https://doi.org/10.1007/s10803-019-04084-z>
- Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin, A. (2016). Real-world executive functions in adults with autism spectrum disorder: Profiles of impairment and associations with adaptive functioning and co-morbid anxiety and depression. *Journal of Autism and Developmental Disorders, 46*(3), 1071–1083. <https://doi.org/10.1007/s10803-015-2655-7>
- World Health Organization. (2022, October 1). *Ageing and health*. <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>

Zeidan, J., Fombonne, E., Scora, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022, March 03). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778–790.
<https://doi.org/10.1002/aur.2696>

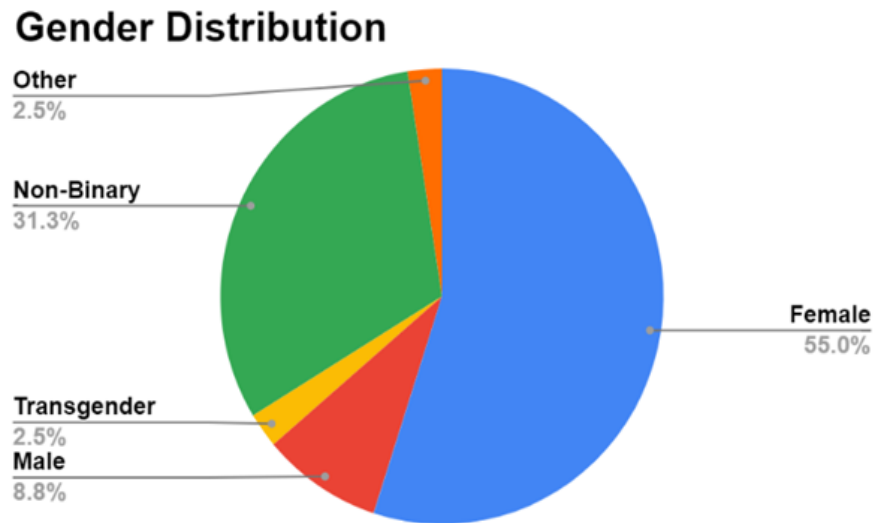
Table 1*Lawton IADL Categories and Corresponding Classification of Participants*

LAWTON IADL SCALE	Number of Participants
Ability to use telephone	Total
Dials a few well-known numbers	11
Operates telephone on own initiative, looks up and dials numbers	60
Answers telephone, but does not dial	2
Does not use telephone at all	7
Shopping	Total
Takes care of all shopping needs independently	49
Shops independently for small purchases	17
Needs to be accompanied on any shopping trip or assistance using application	10
Completely unable to shop	4
Food Preparation	Total
Plans, prepares, and serves adequate meals independently	36
Prepares adequate meals if supplied with ingredients	17
Heats and serves prepared meals or prepares meals but does not maintain adequate diet	19
Needs to have meals prepared	4
Needs to have meals prepared and served	4
Housekeeping	Total
Maintain house alone with occasion assistance (heavy work)	26
Perform light daily task such as dishwashing, bed making	18
Perform light daily tasks, but cannot maintain acceptable level of cleanliness	21
Need help with all home maintenance tasks	14
Do not participate in any housekeeping tasks	1
Laundry	Total
Does personal laundry completely	61
Launders small items, rinses socks, stockings, etc	9
All laundry must be done by others	10
Mode of Transportation	Total
Travel independently on any form of public transportation or drives own car	60
Arranges own travel via taxi or uber, but does not otherwise use public transportation	8
Travels limited to taxi or automobile with assistance of another	6
Does not apply	3
Responsibility For Own Medication.	Total
Responsible for taking medication in correct dosage at correct time	68
Takes responsibility if medication is prepared in advance in separate dosages	8
Is not capable of dispensing own medication	4

Note: The table presents the number of participants who responded for each Lawton IADL category, along with the corresponding classification. The classification indicates the level of independence in daily activities for each participant as assessed by the Lawton IADL scale.

Figure 1

Pie Chart Describing Gender Distribution

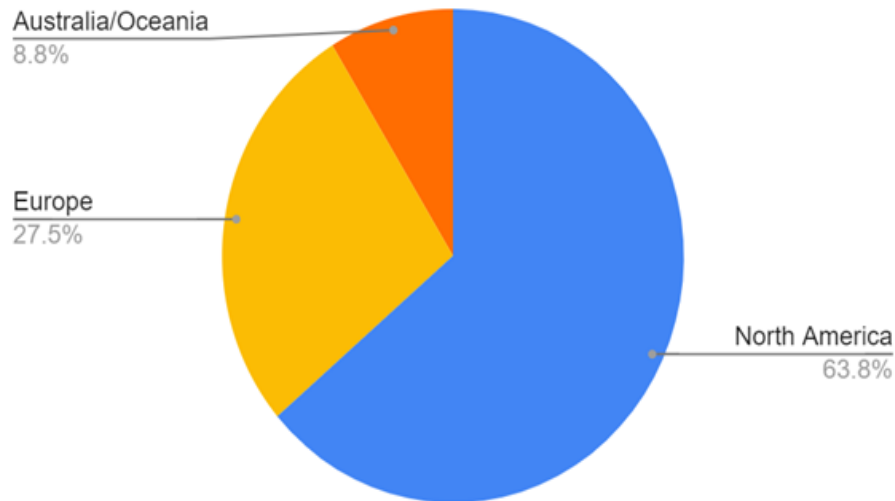


Note: The pie chart illustrates the distribution of gender among participants. Each segment represents the proportion of participants from a specific gender.

Figure 2

Pie Chart Describing Continent Distribution

Continent Distribution

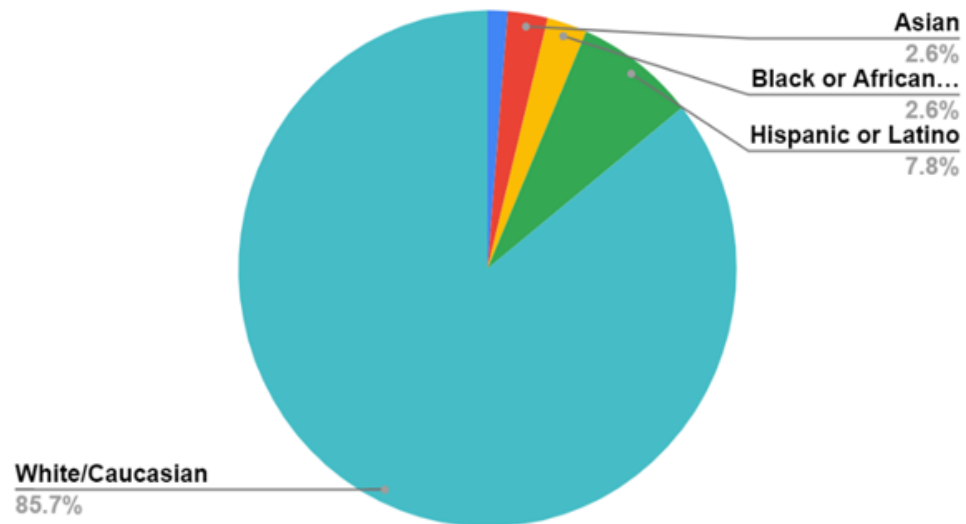


Note: The pie chart depicts the geographical distribution of the participants across different continents. Each segment represents the proportion of participants from a specific continent. This distribution provides insight into the global representation of the study sample.

Figure 3

Pie Chart Describing Ethnic Background

Ethnic Background

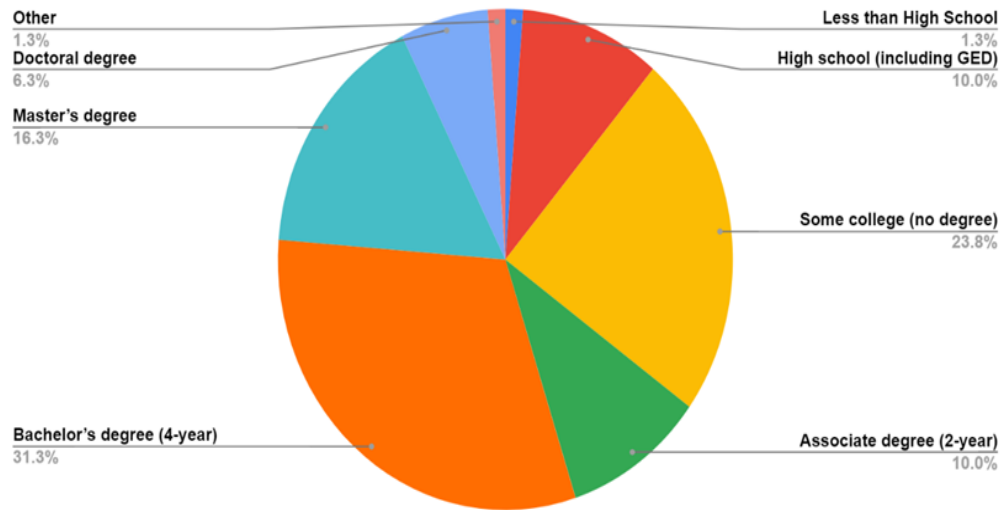


Note: The pie chart illustrates the ethnic background of participants in the study. Each segment represents the proportion of participants from a specific ethnic background.

Figure 4

Pie Chart Describing Level of Education

Level of Education

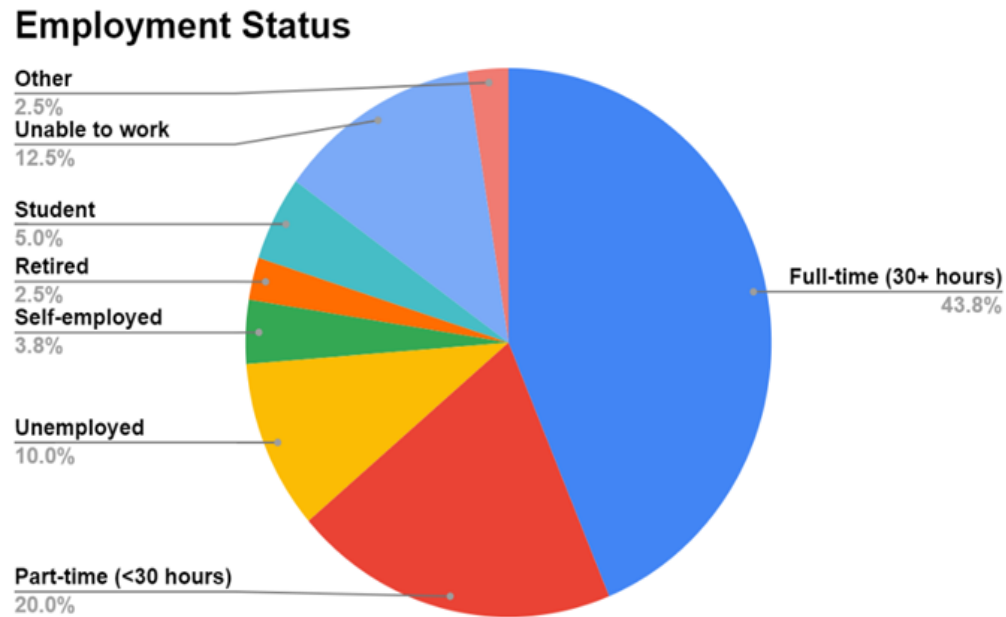


Note: The pie chart illustrates the distribution of participants based on their level of education.

Each segment represents the proportion of participants with a specific educational attainment.

Figure 5

Pie Chart Describing Employment Status



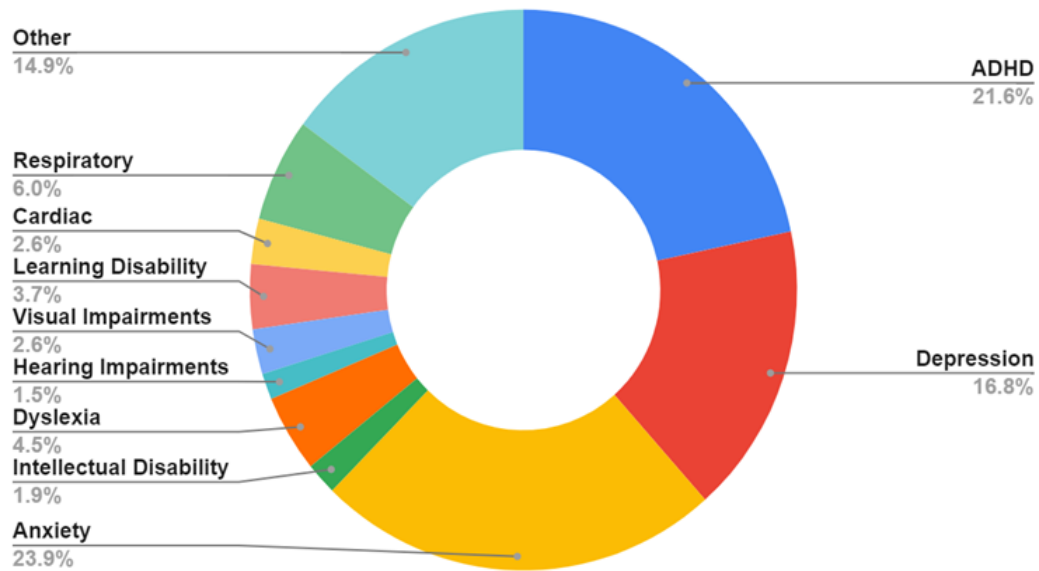
Note: The pie chart depicts the distribution of participants based on their employment status.

Each segment represents the proportion of participants in different employment categories.

Figure 6

Pie Chart Describing Reported Health Conditions

Reported Health Conditions



Note: The pie chart shows the prevalence of other co-occurring health conditions among participants. Each segment represents the proportion of participants with specific health conditions.

Appendix A**Institutional Review Board Approval**

04/11/2024

Subject: IRB Approval Notification Study - IRB Application #02MSOTRS002

Hello,

After review of the requested revisions to your IRB application for Study ID #02MSOTRS002 it has now been approved by the IRB and you may initiate your study at this time. NOTE, this approval is limited to the activities described in your IRB application. Any anticipated changes require submission of an IRB Modification Form, with subsequent IRB approval required, prior to initiation of those changes to the approved protocol or supporting study materials (including your approved recruitment materials, study instruments, and consent documents). Note this also includes a prospective submission of an IRB Modification Form for a change in the total number of subjects stated in your approved IRB application, with NO additional subjects enrolled until you have received IRB Modification application approval.

Congratulations and we wish you success with your thesis project.

Sincerely,

Julie Grace

IRB Chair

Appendix B

Survey Instrument Free Response Questions

Autistic Adult Survey Questions

Free Response

This is the last section of the survey. Please take your time to provide detailed, long, and thorough responses. Your insights are valuable to our study. Feel free to share specific examples or elaborate on your experiences to help us better understand your perspective. The following term will be used in the question. Aging in place is the ability for you to stay and live in your own home as you get older.

Question: Reflecting on your current living situation, can you identify and share some specific challenges and supports that you have encountered that have played a role in your ability to age in place?

Question: After reflecting and completing the question above, do you believe you are currently aging in place?

Possible Responses: Yes, No, Not Sure.

Based on the question above, briefly explain your response below. Are you aging in place, why or why not?

Caregiver Adult Survey Questions

Free Response

This is the last section of the survey. Please take your time to provide detailed, long, and thorough responses. Your insights are valuable to our study. Feel free to share specific examples or elaborate on your experiences to help us better understand your perspective. The following term will be used in the question. Aging in place is the ability for the autistic adult to stay and live in their own home as they get older.

Question: Reflecting on the autistic adults' current living situation, can you identify and share some specific challenges and supports that they have encountered that have played a role in their ability to age in place?

Question: After reflecting and completing the question above, do you believe the autistic adult you are caring for is currently aging in place?

Possible Responses: Yes, No, Not Sure.

Based on the question above, briefly explain your response below.