

Autistic Experience and Aging: A Neurodiversity-Affirmative Approach

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Despite a greater understanding of the diversity of autistic experience overall, very little research examines the experiences of older autistic adults. This narrow focus leaves older autistic adults underrepresented in the research literature, policy discussions, and service planning. This gap is particularly striking given that the majority of autistic people are adults. Many who were formally identified in childhood or emerging adulthood during the 1970s, 80s, and 90s are now entering older age. Increasing numbers of adults are formally identified in middle or later adulthood as understandings of autistic experience have evolved. We recognize that many adults are identified as autistic later in life, which has led research and services to categorize anyone over 50 as “older autistic adults.” However, this broad classification overlooks the significant differences in support needs between someone in their 50s and someone in their 70s. It also fails to reflect how many people in their fifties do not consider themselves older adults. As one study participant in this special issue powerfully stated: “Our existence as whole individuals does not evaporate at age 50.”

This special issue on aging promotes work to address this critical research gap. Research with older autistic adults remains sparse, fragmented, and is often within conceptual frameworks that pathologize rather than develop understandings of autistic experiences of aging. This is at odds with the growing body of work based on the neurodiversity paradigm to take a neurodiversity-affirmative approach to understanding and supporting autistic people throughout the life course. This gap has profound consequences. There are risks of misdiagnosing signs of autistic aging with signs of pathology, such as dementia. Health and social care services are unprepared for the needs of aging autistic adults. Policy fails to account for their priorities and concerns. Opportunities to learn from lived experience and wisdom are missed.

We have a commitment to advance knowledge about autistic aging through a neurodiversity-affirmative lens. Within a neurodiversity-affirmative framework, being autistic is a different, valid neurotype with a distinct developmental trajectory (see Hartman et al.^{1,2} for more detailed information on this approach). From the outset of developing this special issue, we called for papers that approached autistic experience from an

affirming perspective. This commitment reflects a fundamental shift in how we understand and talk about autistic experiences of aging and older autistic people.

This special issue aims to highlight the paramount importance of research that centers autistic people throughout the whole research journey, respects autonomy, and benefits autistic people. The timing of this work is particularly significant. First, demographic shifts mean we are entering an era in which larger cohorts of formally identified autistic people will reach older age than ever before. Healthcare systems, residential care facilities, and social care services must prepare for this reality but currently lack the evidence base to do so effectively.

Second, the research landscape is changing, and research funders are highlighting the need for meaningful impact and involvement of people and communities. Funders such as the National Institute for Health Research and UK Research and Innovation have developed funding streams supporting community partnerships. Similarly, organizations like the Patient-Centered Outcomes Research Institute in the United States emphasize person-centered approaches.

Third, autistic-led organizations, online communities, and advocacy groups are articulating research priorities, challenging harmful practices, and demanding change. Autistic people in all stages of life must be included in the life cycle of research in order to ensure that research is beneficial to them and the community as a whole.

Within this special issue, we must also address a paradox: while we are committed to neurodiversity-affirmative principles, researchers work within a landscape shaped by decades of deficit-based frameworks. Although this landscape is changing, the pace of change differs across countries and cultures. Many autistic people grew up and have reached older age within an era where autistic experience was poorly understood, misidentified, mistreated, or indeed not recognized at all. The intersectionality of aging and autistic experience is an important one to consider, along with the intersectionality of other marginalized groups. Many may have masked their autistic selves to cope within neurotypical worlds (*c.f.*³), while others may not recognize themselves as being autistic. These challenges reflect deeper structural issues

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and epistemic injustice about whose knowledge counts and who is included in research, policy, and practice decisions.

This special issue brings together seven papers and a roundtable discussion examining diverse aspects of autistic aging. Together, these papers span quantitative and qualitative methodologies. They involve in-depth examination of lived experience, including hundreds of participants across multiple countries, and address topics from architectural preferences, examining hospice utilization through insurance records, to the lived experiences of getting older. They highlight what we are beginning to understand, identify existing gaps, and provide suggestions for future research.

The Papers

The papers cover a wide range of topics and methods; however, recurrent themes did come through. These themes included: concern about inadequate support from healthcare staff, lack of understanding of intersectional needs and these needs being met, challenges of adjustments being articulated and met, and age-related conditions like dementia and menopause alongside cognitive changes due to aging. Exploring autistic adults (aged 18–88) aging concerns and priorities, Birtwell et al. (2025) note that while some autistic people reported autistic life becoming “easier” with age, others found it harder.^{4,5} Exploring autistic lived experiences of retirement, Davies et al. (2025) highlight the impact of time on older autistic adults, both in terms of life trajectory, particularly the unexpectedness of retirement and the distinct way autistic people experience this transition, and in terms of inadequate support systems. Central to these challenges are shifts in identity and purpose, and the difficulties that arise in managing increased unstructured time.⁶ Closely associated with the impact of time and transitioning in autistic later life is the matter of space. Exploring architectural needs and preferences in residential care facilities, among autistic people, Ponting et al. (2025) highlight the differing impact of residential care design on the experiences of autistic and non-autistic people in terms of sensory challenges, social interactions, and day-to-day life elements.⁷ While care design positively impacted non-autistic people’s well-being and quality of life, these same features negatively impacted autistic people’s well-being, including causing distress, discomfort, and limiting their ability to undertake daily tasks. The study findings challenge the assumption that “buildings for autistic people are better for everyone.” Conventional building and acoustic design tend to assume a non-existent average user and fail to apply universal design principles that would make environments accessible and usable for all people.^{8,9} Indeed, the authors suggest that flexible private spaces and varied shared spaces offering residents meaningful choices should be included within design.

Chen et al. (2024) highlight the importance and impact of the sensory environment on older autistic people.¹⁰ In their exploration of autistic aging, Chen et al. (2025) focused particularly on sensory processing differences and mental health in participants aged 40–93. The impact of sensory processing differences increased across adulthood for autistic participants, and these sensory processing differences were associated with increasing anxiety/depression. Older autistic adults needed additional support with their sensory processing differences, which is an important consideration for service/care

delivery, design, and planning. Throughout the research, there are themes of choice and autonomy regarding healthcare access. These are highlighted in the roundtable (Stewart et al., 2026),¹¹ for example, having quiet spaces to wait in and being able to communicate asynchronously with healthcare staff.

In their Insight Essay on primary health care, Jarrell clearly describes the challenges of implementing adjustments,¹² such as how to make the waiting room experience for autistic patients less stressful.

The door slams again and the key in my back turns another ninety degrees. I know that this isn’t doing my blood pressure any good.”

They also describe a feeling of being an imposter, would everyone not benefit, and questions: “*Do I require any more help with accessing health services than perhaps a refugee or asylum seeker, a woman of colour or a person experiencing mental health difficulties?*” These words speak to a recent policy report by Stewart and Nisbet^{8,13} in which they discuss the *health labour* that *seldom-listened-to*^a people often experience when accessing healthcare. While in the roundtable (Stewart et al., 2026),¹¹ Mary Doherty’s words resonate with Chris Jarrell’s regarding that for autistic people, adjustments are essential, rather than a preference.

In contrast to studies noting barriers to health care and associated adverse outcomes among autistic adults,¹⁴ Bishop et al. (2025) analyzed Medicare hospice claims data from 5468 autistic older adults and 10,934 matched comparisons who died between 2013 and 2021.¹⁵ Using multivariable logistic regression, researchers found no significant differences in hospice utilization patterns between autistic and non-autistic older adults, whether examining any hospice use, early, intermediate, or late enrollment. The study suggests that utilization patterns were similar between autistic and non-autistic older adults in accessing hospice care.

Tomaszewski et al. (2025) examined adaptive behavior trajectories using longitudinal clinic records from 270 individuals tracked from age 1 to 55.¹⁶ Adaptive behavior includes the conceptual, practical, and social skills to support an individual’s everyday life. It is important to note that diagnostic criteria and approaches have changed dramatically across this time period. A linear spline model revealed that caregiver reports of adaptive skills grew from childhood to young adulthood (ages 1–20) but declined from young adulthood to mid-adulthood (ages 21–55). This study highlights the need for longitudinal research from autistic people’s perspectives and the challenges in conducting longitudinal research, including historical changes in diagnostic criteria, awareness, and the shift from deficit-based to neurodiversity-affirmative approaches.

Conclusion

These studies collectively demonstrate that while research on autistic aging has begun, we remain at an early stage of understanding. Many older autistic people may not have been formally identified in mid- or later adulthood, while

^aTerms coined in the Stewart and Nisbet (2025) report.

others remain unidentified to this day. Historical cohort effects must be considered as these affect our understanding of aging trajectories versus generational differences.

Across all studies there remain issues with sampling and representativeness. There can be biases toward digital literacy, access to technology, and written communication. Indeed, there remains a lack of representation from those who do not use speech or written communication. In these instances, historically, caregiver reports were used rather than including those who are central to understanding the lived experience. People from marginalized backgrounds, such as those marginalized by ethnicity, gender, or sexuality, remain underrepresented in research, and there is an overreliance on existing networks.

There are excellent projects which use a range of communication methods to ensure that those who are *seldom-listened-to* within research are at the center of research. Research funding should prioritize and resource inclusive recruitment strategies including community partnerships, multiple communication formats, compensation for participation, and specific outreach to underrepresented groups.

We recognize that this selection of papers is mainly based on Anglo-Saxon contexts and therefore highlight the importance to include international studies from across different countries and cultures to examine how policy frameworks, health care systems, and cultural contexts shape autistic aging experiences. We also recognize that the selection of papers does not acknowledge economic aspects such as employment and housing, relationships, family and intergenerational dynamics, perspectives on death and dying, intersectional effects including impact of, for instance, menopause, place-based factors including urban versus rural experiences, migration and displacement, or transitions from middle to older age and to later life, or issues relating to frailty.

We acknowledge that there are challenges in the area. We call for longitudinal studies with younger autistic adults to understand trajectories prospectively, while acknowledging that diagnostic criteria, societal awareness, and available supports continue to evolve. There is a need to understand how experiences and needs change over time, and how intersectionality and co-occurring conditions affect outcomes. Greater exploration and autistic-centered understandings of what “good” (or “successful”) outcomes look like in older age with older autistic people are also needed.

The limitations identified reflect epistemic injustice, the historical dominance of deficit-based frameworks, exclusion of autistic people from decision making in research and service design, inadequate investment in appropriate supports across the lifespan, the homogenization of experience, and failure to recognize the intersectional identities and diverse needs of autistic people.

To address these limitations, future work must prioritize neurodiversity-affirmative methodologies that center autistic perspectives; participation from diverse communities including those who are seldom-listened-to ensure that all are included in shaping the research agenda; a mix of research designs and methodologies which can capture the multiple dimensions of complex phenomena; intersectional approaches recognizing multiple marginalized identities;

and developing a strong evidence base so that there can be effective translation into practice.

The papers in this special issue give us insights into the range of methods and types of data that can help support research development in this area. They give us insights into retirement, sensory processing challenges, longitudinal studies, how care is accessed and utilised, as well as help us focus on research needs for future care.

Autistic adults consistently identify three priorities for aging well: maintaining physical and mental health, preserving independence and autonomy, and sustaining social connections on their own terms.

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