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Ageing on the autism spectrum

The Psychologist – January 2024

Publicly available here: <https://www.bps.org.uk/psychologist/ageing-autism-spectrum>

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When I first became involved in research on autism and ageing in 2015, it was feasible to sit down with a cup of coffee and read through the entire literature in an afternoon. As an eager undergraduate, that was what I did. At that time, research papers involving autistic people in midlife and older age were often descriptive case reports or small-scale studies, with male-dominated demographics, and often reported inconsistent findings. In the years since, the autism ageing research landscape has dramatically changed.

Last year, my colleagues at King's College London and I conducted an impressionistic review to explore how the autistic ageing research landscape has evolved over the past decade. We found that there has been a near threefold increase in the number of publications focusing on autism in midlife and older age. Despite this, we also found that less than 1 per cent of the overall autism research literature has focused on older people. So, while this expansion of the literature is reassuring, there is still a lot of work to be done to ensure autistic people in midlife and older age are understood and receive the support they need as they age.

Autism is not a 'new' condition; autistic traits were first clinically described in the 1920s, autism characterised by Asperger and Kanner in the 1940s, and included in diagnostic manuals in the 1980s. Since then, major changes have occurred to the diagnostic criteria for autism, including broadening a once 'narrow' spectrum, meaning that individuals diagnosed with autism today are likely to exhibit different autistic characteristics compared to those diagnosed in the 1980s or earlier.

A study by O'Nions and colleagues emphasises the relevance of this to older people. Their study of primary health care records indicates that, as of 2018, approximately 1 in 34 children had an autism diagnosis compared to only 1 in 6,000 older adults. Three in four autistic people in the UK may be undiagnosed, and this is likely to be disproportionately impacting middle-aged and older people, particularly women, forming a lost generation of autistic people.

In response to these issues, autism researchers have taken two approaches to expand our understanding of ageing on the autism spectrum.

The first, the dimensional approach, explores autism as the extreme of a continuum of traits and characteristics. Using this approach involves identifying those with high autistic traits and using this as a proxy for diagnosis. While there is no guarantee that these 'high trait' people are undiagnosed autistic individuals, the dimensional approach can be easily

implemented in large-scale studies and can be used to generate hypotheses for further study in diagnosed autistic groups.

The second, the categorical approach, explores the experience of those who have an autism diagnosis, often first obtained in adulthood. This approach can be expanded to include those who self-identify as autistic, but who do not have a clinical diagnosis. While these approaches do have key differences, they are complementary and helpful for generating information about the lived experiences of those ageing on the autism spectrum.

Both approaches have been successfully implemented to explore a broad range of research topics that address the important question of 'what happens to autistic people when they get older?'. For example, studies using the dimensional approach have identified a range of differences in middle-aged and older people who have high or low autistic traits across domains. In the health domain, middle-aged and older people with high autistic traits have been found to have high rates of most psychiatric conditions and mental health crises, some physical health conditions, and to report worse sleep quality.

In the domain of cognition, this group has been found to have subtle differences in their general cognitive abilities, as well as their socio-cognitive abilities. They also self-report more cognitive decline than those with low autistic traits. In life experiences, this group have been found to report high rates of childhood and adult trauma, including emotional neglect/abuse and sexual abuse, associated with high rates of post-traumatic stress disorder symptoms. Finally, studies looking at biomarkers have identified a faster pace of ageing, compared to those with low autistic traits.

Studies using the categorical approach have found a similar pattern of results, particularly in areas related to health and cognition. However, work still needs to be done to further examine life experiences and biomarkers in autistic populations. Additional studies involving either diagnosed or self-identified autistic adults have found that autistic people in midlife and older age often have poorer normative life outcomes than non-autistic peers. Furthermore, middle-aged and older autistic people often report having a lack of support and being less socially connected than non-autistic people, and this is associated with lower quality of life.

These findings tell us that older autistic people may require additional support as they age. Future research should involve longitudinal methodologies, as it is only through tracking change with age that we can evaluate how the profiles and support needs of older autistic people change throughout later life. Relevant support may include ensuring older autistic adults have access to healthcare support for their mental health, addressing potential social barriers to prevent them from becoming socially isolated, and ensuring that they have security in their finances and housing needs in later life. However, there is little evidence-based research about how to best implement support for older autistic people and importantly, autistic people themselves should be involved in identifying how support is implemented and tailored, as it is unlikely that a one-size-fits-all approach will be sufficient.

As researchers and clinicians, we could look to well-recognised autistic people in older age for inspiration for how people can reap the benefits of support. Donald Triplett, who was Kanner's 'Case 1', died at 89 years old in June 2023. Donald was embraced by his community throughout his life and modelled a happy older age. He worked in a supportive environment for nearly seven decades, and pursued hobbies and interests, such as golf, well into later life. Donald's life exemplifies that when people are supported, they can thrive and as a researcher, that is what motivates me to continue my work in autism and ageing.