# Editorial


## Author

Bowler, Dermot M, Geurts, Hide M, Howlin, Patricia



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# Editorial

**Dermot M. Bowler, Hilde M. Geurts & Patricia Howlin**

It has taken us a surprisingly long time to realise that, just like everyone else, autistic people grow old too. This issue of RASD marks the first ever special issue of a scientific journal devoted to ASD in later life - over 70 years since the first clinical description of Autism Spectrum Disorder (ASD) in children. The articles in this issue are testament to how seriously scientists and clinicians are now taking the challenges of ageing and autism, with contributions ranging from the identification of neural networks underlying verbal fluency to the development of appropriate measures of quality of life.

In the first article, Roestorf and her colleagues set the scene by reporting the conclusions of a series of Special Interest Group (SIG) meetings on older adults with ASD held at the annual conference of the International Sociey for Autism Research (INSAR) in 2016 and 2017. The aim of these meetings was to bring together scientists and clinicians working in the field to identify common research themes and to discuss appropriate strategies to investigate them. Among the issues that emerged were the question of when old age begins in the autistic population, how diagnosis might be made in later life, what cognitive assessments might be appropriate for this group and what, if any, treatment and care approaches might be useful in the context of ASD. The need for collaboration and data sharing between research groups was also highlighted and, in this respect, an important outcome was to agree a set of core principles guiding the gathering of background information about participants in all future studies. But perhaps the most important outcome was the consensus that autistic people themselves should be involved in the formulation of research questions and the design of assessments.

The next two papers in the issue expand upon existing findings that have identified poorer Quality of Life (QoL) in older autistic adults. Mason and colleagues report a study using the World Health Organisation's measure of QoL and the Hospital Anxiety and Depression Scale with a group of autistic adults over 55 years of age. They found that people who met clinical cut-offs for anxiety and depression had significantly lower QoL. They did not, however, find that QoL scores were associated with self-reports of 'normative outcomes' in the areas of employment, friends, living arrangements and degree of support received. These sometimes counter-intuitive findings highlight the need to

develop more refined measurement instruments and a more sophisticated conceptual analysis of QoL and how it interacts with the lived experience of people with autism as they grow older. The theme of QoL is further explored by Kim and Bottema-Beutel, who use meta regression analysis of existing published data to explore correlates of QoL in a large sample of adults on the autism spectrum. Their systematic literature search yielded 17 studies containing 1721 participants and yielding 165 effect sizes relating to studies of QoL in relation to age, autism severity, IQ and social functioning. Their participant group ranged in age from 18 to 63 years which spans the age of transition to older age that was discussed at the SIG meetings described earlier. Overall, the pooled findings revealed little significant impact of age, IQ or autism severity but a significant effect of social functioning on level of QoL, leading the authors to conclude that that interventions should be aimed at improving social functioning.

Existing literature also points to a higher degree of physical and mental health difficulties as well as shorter life expectancy in some older autistic individuals. In their paper, Bishop-Fitzpatrick and Rubenstein expand on this work by analysing the effect of having an intellectual disability (ID) on the rate of claims for physical and mental health conditions adults with an ASD, drawing on data from claim records of the state of Wisconsin Medicaid system from adults with ASD aged from 40 to 88 years. The authors' findings suggest higher prevalence of physical and mental health conditions in their sample of middle-aged and older individuals with ASD compared to earlier findings with younger participants. Although overall, there were no statistically different differences in broad categories of physical and mental health between individuals with or without accompanying ID, people without ID tended to be less likely to have epilepsy and more likely to have anxiety or depression than those with ID. The authors suggest that generalist health practitioners need to be made aware that a diagnosis of ASD is likely to bring with it a range of other physical and mental health conditions and that this likelihood increases as people get older.

The fifth paper in this issue, by Moss et al is a report of a 20-year follow-up of siblings (average age 40 years) of people diagnosed with ASD in childhood. Earlier studies of these siblings report that 6% had a diagnosis of ASD and 20% had the broad autism phenotype. The aim of the study reported here was to document the "unaffected" siblings' experiences of growing older with an autistic brother or sister. The siblings were found to have an overall high level of functioning in terms of IQ, relationships and social functioning and although over 90% reported some negative experiences resulting from having an autistic sibling, strongly negative experiences were reported by only 7% of

the sample. What was particularly interesting was that level of reported negative experiences was not associated with the presence of mental health difficulties. Participants also reported concerns about the ongoing care of their autistic sibling when their parents die, thus highlighting a major policy implication of the findings.

The final two papers in this issue switch focus to a very different but equally important aspect of growing older with ASD; the neural underpinnings of behavioural systems and how these change over time. Baxter and colleagues used fMRI to investigate age related differences in the neural networks activated during a phonemic fluency task. The authors compared young (18-25 year old) and middle aged (40-60 year old) adults with and without ASD and predicted greater age-related differences in frontal activity in the ASD group on the basis of the cumulative association between age and ASD with frontal lobe function. In line with earlier research, the authors failed to find age-related changes in fluency and attribute these to the possible development of compensatory mechanisms.

From the same team of researchers, Walsh and colleagues sought to identify any age-related differences in the relation between ASD-related social functioning and executive dysfunction. They hypothesised that age-related differences in neural connectivity associated with executive dysfunction would predict ASD-related social difficulties. They compared the scores of young and middle-aged adults, with or without an autism diagnosis, on the Social Responsiveness Scale (SRS) and the Tower of London (ToL) test and explored functional connectivity of the resting state executive network and the dorsolateral prefrontal cortex. Surprisingly, their results did not reveal diminished SRS scores in older ASD individuals, but did show diminished executive function network connectivity, which, along with the behavioural ToL measure, correlated with SRS measures in the older ASD participants. This suggests a potential scaffolding role for executive functioning in the later- life social functioning of ASD individuals. But as the authors point out, such a conclusion needs to be confirmed by means of longitudinal research.

Each of the seven articles in this special issue illustrate in their own way the challenges and complexities of studying older age in ASD. Almost all of the studies could be criticised in that they included middle-aged as well as old participants. In some cases, this was because of the difficulty of recruiting sufficient numbers of participants over the age of about 65 years but in others it enabled

the adoption of a broader, more life-span perspective. In either case, the inclusion of 'young-old' or middle-aged participants can be looked upon as a strength, especially in view of the now considerable body of research showing that, at least in some respects, younger autistic adults are already cognitively old (see for example, Lever & Geurts, 2016; Ring, Gaigg, & Bowler, 2016; Roestorf, 2019). The question of what constitutes an 'older autistic person' is not as simple to answer as it first seems, and the presupposition that the onset of age-related cognitive change is the same as in the typical population could be thought of as an inappropriate, normocentric imposition on a population whose very identification relies on the notion of a different developmental trajectory. Consequently, there is a need to study samples of autistic adults of 70, 80 and even 90 years of age in order fully to understand the life-span trajectory in this population. The situation should improve as more and more middle-aged and late-middle aged adults are recruited into participant databases. Moreover, as noted in Roestorf et al's report from the SIG meetings at INSAR, collaboration among research teams should improve the statistical power of investigations, with a consequent enhancement of the quality of the resulting science. Regular collaborative meetings to formulate agreed testing protocols and to foster co-operation across research teams should also help to lay the foundations of longitudinal research, which, as several of the papers in this issue have noted, is the only meaningful way to answer some research questions. Perhaps the biggest challenge of all is to persuade funding bodies to support such studies, since longitudinal research at this end of the life-span needs to be carried out over a period of decades rather than years. For now, it is important to keep in mind, that the field of old age research in autistic adults is rather young, so we should be careful in drawing strong conclusions. First, a larger body of converging evidence is needed. The studies reported on in this special issue are, we hope, just the start of a new and important research domain.

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