Why we need research about autism and ageing

Neurotypical adults and their families aspire to a high standard of care as they grow older. The knowledge that this care is available, supported by research, and monitored and delivered by trained professionals provides reassurance. Autistic people are entitled to the same level of support as other people, but structures to ensure this support do not exist outside of policy documents and some rare centres of excellence.

Many of us, autistic people, wonder how our old age will look like, and we do not have answers. Knowing there is such a paucity of research about supporting us as we grow older makes old age a frightening prospect. I ask,

Who will look after me if I need care? How will I survive a long stay in a hospital? Will a care home pressure me to join in social activities because that is what neurotypical people want? How will I be judged by my peer residents, if I don’t make small-talk or gossip? If sensory overload or anxiety leads to a meltdown, will I be shunted straight to the dementia ward?

Research into any lifelong condition usually follows the lifespan of individuals with that condition as a way of understanding its trajectory and to provide a point of reference against which the success of interventions can be marked. Yet, with only a few exceptions, autism research has generally excluded autistic people over the age of 40 years (Howlin and Moss, 2012; Povey et al., 2011). We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age.

There is so much to learn. What is the long-term outcome of autism interventions such as selective serotonin reuptake inhibitors (SSRIs) or behavioural interventions? Understanding of the experience of older generations has the potential to affect the support offered to younger people.

What we do know is that there is a much greater risk of premature mortality in autism (Heslop et al., 2013; Hirvikoski et al., 2016); on average, autistic people with additional intellectual disability die 30 years before non-autistic people (Heslop et al., 2013) – with epilepsy identified as the biggest cause of premature death in this group – and those autistic people without an intellectual disability die 12 years earlier than typical adults. We do not know why the risk of premature mortality is so high. Without research into its potential precursors, professionals lack the tools to combat this high death rate. Why invest resources in researching autism interventions in earlier years and then ignore their long-term outcomes or monitor the trajectory of autistic lives to their conclusion?

Those autistic people who do not die prematurely are likely to go through major ageing-related life changes, which commence in middle age. Arthritis, menopause, type 2 diabetes and many forms of cancer are all generally regarded as conditions of middle and older age – but we have very little knowledge of the prevalence of these conditions in older autistic adults and the potentially substantial effects they have on autistic people’s lives.

We know that autistic people have sensory differences, but again, we know nothing about how these are influenced by ageing. Why not? Autistic people often live with high stress and anxiety, which can intensify some mental and physical health conditions (Mukaetova-Ladinska and Coppock, 2016). Common responses to the psychological pain of anxiety are over-eating, poor sleep, alcohol abuse and self-harm (Croen et al., 2015). Suicide is the self-medication of last resort and there is emerging research evidence showing increased rates of suicidal thoughts in autistic adults compared with neurotypical adults (Cassidy et al., 2014).

Cognitive changes and various neurological conditions are important areas of research not only for how they affect autistic people but also for how they may manifest differently than in ageing neurotypical people. Currently, ongoing research in the United Kingdom is investigating cognitive decline in autistic adults and the interconnection between that decline and dementia. There is a theory that autistic people may cope better with or be protected against the effects of cognitive ageing, which, if true, could inform dementia research in the general population (Lever and Geurts, 2015).

Away from the medical sphere, there are many social issues that warrant investigation. For example, many ageing autistic people are supported by very elderly parents, causing extreme anxieties about their futures (Rosenblatt, 2008). In the area of employment, getting and holding a job and access to disability benefits are particularly difficult when employers and benefits assessors are largely
ignorant of the impact of being autistic. As adults age, it can become increasingly difficult to change direction and compete with ever-younger applicants, so the talent and life chances of older people often are wasted. Poverty in old age is another serious issue for those whose lives have never included the ability to save for a pension.

Service providers in the United Kingdom have a statutory duty to provide appropriate care for autistic people as we grow older. Where is the quantitative or qualitative analysis of best practice outcomes required to frame appropriate support? (Povey and Michael, 2016). And where is the training for this particular workforce to support communication and decision-making for older autistic people? There is an urgent need for autism trained advocates, particularly Independent Mental Capacity Advocates (Boehm, 2013). With scant awareness of adult autism among care and support professionals, autistic people will find their needs unmet, as they lean on home and residential care, hospitals and social services for older people.

To date, there are a few high-quality autism and ageing research projects (Howlin and Lounds Taylor, 2015). The ASD Lifecourse, Adulthood and Ageing project, based in Newcastle, UK, has begun engaging adults on the autism spectrum and their relatives in research, and there are groups in Australia, Denmark, and the United States conducting similar research. Researchers and funders expect high-quality support and care for their own families in their middle and later years and autistic people want the same. If we are to receive this support, it is obvious that research is necessary both to inform and equip those who provide it. To be blunt, because autistic people can be blunt – why do I even need to argue the case for research into autism and ageing?

References


Cos Michael
Autism and Ageing Consultant and Autistic Speaker
www.autismage.com