

Autism and ageing: issues for the future

Recognising the needs of autistic adults is now an expectation enshrined in law, but little attention has been paid to the issues affecting older people with the condition. What is certain is that a significant challenge remains to ensure that adults with autism enjoy fulfilling and productive lives as they age.

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In October 2009, the Autism Act (in England) was passed, which put an expectation on local authorities to recognise the needs of adults with autism. This landmark legislation resulted in *Fulfilling and rewarding lives. The strategy for adults with autism in England*.¹ This strategy describes a vision where all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them.

These are bold aspirations, but what do we know about people with autism as they age? Despite progress in our understanding of autism, relatively little attention has been paid to date to the process of ageing² and what we can do to ensure that people with autism have the same opportunities as other citizens to live healthy, fulfilled lives as they age.

Autism is a lifelong condition, which is now thought to affect one in 100 people.³ While it was first recognised as a distinct syndrome in the

1940s by Leo Kanner,⁴ it was not until 1975 that the concept of autism as a spectrum disorder was described by Lorna Wing and her colleague Judith Gould. Their work recognised that autism affects each person differently, and that though all people with autism have defined characteristics necessary for a diagnosis, they will vary in severity and complexity. Those key characteristics necessary for diagnosis are known as the “triad of impairments” relating to difficulties with communication, social interaction and social imagination.^{5,6}

The core problems in autism relate to the development of the social instinct (the ability to relate to others) in childhood. Consequently as individuals with autism develop, they usually find huge problems in social understanding and in their relationships with others. For example, they may find no pleasure in sharing company with

others, or may wish to interact but struggle in their understanding of the usual social cues and behaviour. This also affects their ability to communicate with others and to make sense of the world around them, particularly the context of behaviours, motivations and the inner thoughts of other people. Their thinking is likely to be inflexible, and they may have a restricted and repetitive repertoire of activities. As a spectrum condition, autism affects each person differently, irrespective of IQ and level of functioning. Some will need high levels of support throughout their lives, have no language, and very severe challenging behaviours; others will be able to attain academic qualifications and achieve great things in their chosen career, though they may continue to struggle with social relationships and understand the complex social interactions happening around them.

In addition, many have

markedly different sensory experiences to people without autism. This may affect one or all of the senses. Some people report being unable to filter out background noise, an aversion to particular textures in food or clothing, a fascination with particular light patterns, or a hypo- or hyper-sensitive response to pain.

Autism is not a unitary condition and there are thought to be many factors involved in causation. Genetic factors have long been implicated,^{7,8} but these are complex and solutions related to genetic therapies are controversial.

In 2009 the National Autistic Society surveyed 1400 adults with autism, either directly or through their families, to support their campaign to draw attention to the needs of adults with autism. Some 4% (65) of the respondents to the “I Exist” survey were 65 years or over, while 30% (540) were 40–64 years. This makes a total of 605 respondents over the age of 40 (34% of the respondents).⁹

The findings of this survey point to a population who are struggling to have their needs recognised and met. A significantly higher percentage of 40–64 year olds had not received an assessment (a statutory assessment of their needs under the Community Care Act 1990) compared with 18–29 year olds, and the survey showed that a considerable number of adults with autism aged 40 and over remained reliant on family for their support. Very few individuals in any age group received most of their support from friends, and the evidence points to people with autism² becoming more and more isolated as they grow older.

As parents age, they may no longer be able to support their autistic children, but there is evidence that they are not supported by professionals or friends either. This puts a great responsibility onto other family members. When asked about their son or daughter's future, 85% of parents said they had serious worries about what would happen when they were no longer able to support them.

We still know little about outcomes for adults with autism, especially the older age group, or whether there are changes in autism symptoms and behaviours related to the ageing process. Tantam's studies from the 1980s and 1990s¹⁰ revealed a desperate picture of social isolation, high unemployment and mental ill health among the more able population. This view was confirmed by recent work by Stuart-Hamilton and colleagues² comparing adults with autism over the age of 40 with those of the general population, which also points to significant levels of unemployment, anxiety and depression in older adults with autism.

It is suggested by some that brain maturation and adaptation continues well into adulthood, with a consequent reduction in the perceived level of disability for some individuals. It is also suggested that some do in fact “grow out of” autism, in that they no longer meet diagnostic criteria for diagnosis. If this is so, and whether it is due to changes in the brain itself or the individual's successful adaptation to social and environmental conditions, are matters for conjecture. At present we do not know.

In coming to sensible conclusions, we need to know more about the ageing process in general. There is a scant evidence base. More research is needed into the specific issues related to autism and ageing, but it is not enough to wait until we know the answers to these questions. We need to do something now.

The National Autistic Society has introduced a health screening tool to assess personal health and family health history to be completed regardless of age. This will capture essential information that will allow for the assessment of the risk of particular medical conditions that have a familial component such as cancer, heart disease, and diabetes. We have also been developing a bank of resources to help staff working with older people with autism gain a better understanding of how to support people as they grow older. Many care staff who work with people with autism are used to managing younger groups and, therefore, may have had little experience in being with older people. Without good training, they may struggle to understand the issues they face. Similarly, we are developing training, based on the Department of Health framework for older people, which looks at how people with autism can be helped to remain independent and healthy into older age.

We also need better mechanisms for the diagnosis and treatment of comorbid conditions. Dementia rates are increasing, and dementia in the learning disabled population is much higher than in the general population, even excluding Down syndrome. It is important to be

able to recognise possible signs of dementia and refer on for expert help. Nevertheless, changes in behaviour are not necessarily related to dementia. There could be many alternative explanations, and the input of people who know the individual with autism really well is vital in understanding the possible reasons for such changes.

Health issues apart, the social and economic and legal implications of ageing should also be considered. The majority of adults with autism spectrum conditions live with carers in the community, some of whom may themselves be ageing or vulnerable. Local authorities are frequently unaware of their number or circumstances, especially the more able who are not receiving funded services. Their social isolation may be compounded by the sudden loss of a carer, retirement or loss of employment and related network of support. We can only surmise the negative effects on health and longevity of a lifetime of high levels of anxiety, stress or medication (many people with autism have been prescribed antipsychotics over a protracted period).¹¹

When dealing with autism, the boundaries of responsibility for health and social care are blurred, particularly for the more able group. Will their changing needs be recognised and responded to appropriately? Will new government proposals really help? Especially if local discretion is at the heart of entitlement? An ongoing government review into our present system of funding for social care reflects the growing concern at the anticipated numbers of the elderly in need and the inability or unwillingness

of the state to provide it.

Could this be a double whammy for people with autism? Already socially isolated and disadvantaged by their condition and responses to it, will they face additional problems from a system more attuned to the needs of the majority? What of those already settled in residential services? Will their entitlement to funding be lost? Could they be forced to move on from familiar surroundings and people as a consequence of arbitrary budgeting on the part of a local authority? Who will defend or fight for them when their parents are no longer around?

The issues related to autism and ageing are a growing challenge for society. We need to develop ways for people to continue to enjoy fulfilled and productive lives as they grow older. By its very nature, autism provides strong predisposition to a host of social and medical problems (eg, fragile X) and these may be exacerbated with age. We need to ensure that as far as possible, we intervene in a timely fashion to prevent this predisposition becoming a reality. Just as children with autism become adults with autism — adults with autism grow older. As with our response to the transition from childhood to adulthood, we need to deal with the new transition from adulthood into older age. The question from parents “what happens after I'm gone?” is as relevant today as ever.

Conflict of interest: none declared. For information and resources go to www.autism.org.uk

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