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About autism¹

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. More than 1 in 100 people in the UK has autism.²

About the NAS

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We have around 20,000 members and 100 branches, who are at the heart of what we do. We provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign for lasting positive change for people affected by autism, and empower local people to influence change they will experience at a local level.
www.autism.org.uk

The Autism and Ageing Commission

In 2013 The National Autistic Society convened a commission of members of the House of Lords to look at the challenges facing older people with autism and their families, and the ways these challenges could be addressed through policy changes. The findings of the Commission resulted in an NAS report, 'Getting on? Growing Older with Autism' in 2013 and are reflected in this submission.

Overview: Older people with autism

More than 1 in 100 people have autism and recent research indicates that this is consistent across all age groups. The first generation of people diagnosed with autism in childhood are now reaching middle age, while some older adults are being diagnosed for the first time.

More attention is now being paid both nationally and locally to the needs of children and young adults with autism, but older adults are a growing and overlooked group with a specific set of needs that should be addressed.

Local government have a key role to play in enabling adults with autism to live fulfilling lives. Local health and social care services need to take steps to diagnose, assess and meet the needs of older adults with autism. Local authorities and the local NHS also need to plan and

¹ Throughout this briefing, unless otherwise specified, autism is taken to mean all conditions on the autism spectrum, including Asperger syndrome, high functioning autism and classic autism

² Baird G, et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368, 210-215. Reid, B. (2006)

commission services that take into account people's changing needs, take steps to ensure that mainstream services are autism appropriate and that healthcare professionals are sufficiently trained in autism. Key to this is the implementation of the Autism Act 2009 through the local application adult autism strategy for England and the statutory guidance that accompanies it.

Key issues affecting older people with autism

Diagnosis and identification

Research shows that more than 1 in 100 people have autism and recent research indicates that this is consistent across all age groups. However, there appears to be under-diagnosis in the older population across the spectrum.³ We know that a diagnosis is often crucial to being able to access appropriate support and, for some people, enables them to understand themselves fully for the first time.

There are particular barriers to diagnosis for older people with autism. They often struggle to provide information on their developmental history, which professionals routinely examine to reach a diagnosis, as relatives who are able to remember their childhood may have passed away. Older people with autism are also likely to have adapted their behaviour over the years and have developed sophisticated coping mechanisms which disguise their autism. Additional mental health problems may have developed, making their autism harder to identify.

Post-diagnosis, people often need to come to terms with difficulties in their past, perhaps after many years of not fully understanding their own behaviour. They will need support, and may not have informal support networks that can provide this. 45% of people over 45 who responded to an NAS survey said they would like counselling but were not receiving it.⁴

The role for local authorities

- **Supporting the development of clear diagnostic pathways:** Local authorities should work through their local autism partnership board to support Clinical Commissioning Groups in developing and overseeing the development of a clear pathway to diagnosis.

The adult autism strategy for England *Fulfilling and rewarding lives*, its recent update, *Think Autism* as well as the statutory guidance, *Implementing fulfilling and rewarding lives*, made clear that every local area in England should have a pathway to diagnose adults by 2013. Setting up and keeping under review this pathway will include reviewing whether NICE guidelines on diagnosing, assessing and managing autism in adults are being implemented.

NAS research from 2013 showed that there were pathways in place in just 63 out of 152 English local authorities.⁵

- As part of the pathway, **local authorities have a clear role in disseminating information on the pathway** to relevant professionals as well as individuals on how to get an assessment.

³ Bruhga, T. et al (2012), *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 adult psychiatric morbidity survey*. NHS Information Centre.

⁴ Unpublished survey (2012), NAS.

⁵ Ozmen, A. (2013). *Push for Action: we need to turn the autism act into action*. The National Autistic Society.

- The Autism Act statutory guidance also makes it clear that **post diagnosis**, the local authority has a clear role in ensuring individuals are aware that they can have a community care assessment.
- Local authorities should also work with their local Clinical Commissioning Group(s) to ensure that a range of **post-diagnostic support**, as set out in the NICE guidelines is available locally.

Health and care needs in older age

Identifying need

NAS research has found that all adults with autism find it hard to access the help they need, but that older adults, find it harder. This may be because fewer older people with autism have had their needs assessed. An NAS survey in 2012 found that 66% of respondents over 55 have not had their needs assessed since they were 18. Significantly fewer older adults had had their needs assessed in the previous two years, compared to younger respondents⁶.

The lack of data and information on the numbers of adults with autism and their needs is also a specific challenge for local authorities. The Autism and Ageing Commission heard from experts who said that the needs of the older population of adults with autism was not on anybody's radar.

This is a particular issue for those adults who have largely been supported at home all their lives by their families, who will not be in a position to support them indefinitely. A death of a parent or other crisis can be particularly distressing for someone with autism who finds change hard to cope with. Identifying such needs, before the crisis happens will be essential to help minimise the impact.

If older adults with autism are to be properly considered in commissioning, local authorities must collect data and include this data in Joint Strategic Needs Assessments (JSNAs). None of the 15 local authorities to whom the NAS put information requests included people over 65 with autism as a distinct group in their JSNAs.

The role for local authorities

- **Collect data on autism and include in JSNAs:** The Autism Act Statutory Guidance advises local authorities to collect data on the total population of older people with autism in their area to enable them to plan appropriate services for older people with autism.

Social isolation

The widespread problem of loneliness among older people and its impact on physical and mental health is becoming more recognised. Social isolation is high amongst older people with autism and can mean they are less likely to get the support they need.

Across the spectrum, many people with autism rely on their families for support. However, as they age, family members may be less able to provide such support. Statutory services need to be prepared to fill the gap. Few older respondents to NAS surveys received statutory support. One survey of adults in England found that of people living in their own flat or house, 46% of over-65s have most support provided by families and only 8% had most support provided by professionals.

⁶ Bancroft, K. et al (2012) *Autism :the way we are*. The National Autistic Society

The role for local authorities

- Consider the effectiveness of volunteer-led models to support older people with autism when developing local commissioning plans, and fund such services to meet needs.

Example of good practice:

The NAS in Glasgow has developed a Person to Person Volunteer Service. The Service recruits, trains and supports volunteers to provide a range of support to older adults with autism and their carers and families. Support is tailored to individual need. Up to the 31st August 2014, the project has supported 42 people, including 34 older adults and eight carers or family members. The support provided ranges from helping to access activities and sorting through paperwork, to representation at employment dispute and careers guidance.

Advocacy

Families of people with autism also frequently act as advocates for their relative with autism, for example by representing their relative's interests to service providers. Families are concerned about what might happen when they are no longer around to perform this role and are anxious that their relative should have access to an independent advocacy if this were the case.

Recent reforms of the care system mean that, from April 2015, people have new rights to advocacy. Under the Care Act 2014, local authorities will have a duty to provide independent advocacy when someone has 'substantial difficulty' being involved in the care and support process, and does not have an appropriate individual to support them. An older person with autism, for example, who has difficulty communicating, might need an advocate to enable them to effectively take part in a community care assessment or to have a say in a review of their care and support plan.

The role for local authorities

- Ensure adults with autism have access to an independent advocate trained in autism, should they need it.

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