Getting on?
Growing older with autism

A policy report
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THE CLOTHWORKERS’ FOUNDATION
This report would not have been possible without the generous support of The Clothworkers’ Foundation.
Foreword:
Baroness Greengross

I have worked in older people’s policy for over thirty years. During this time I’ve seen dramatic increases in life expectancy, debates over care funding moving to the fore of our national politics, and significant improvements in the legal protections we offer against age discrimination.

During the same period, society’s understanding of autism has taken great steps forward. However, national and local policy-makers, as well as the media, very often concentrate on the effect of the disability on children. Only in the past four or five years has any real attention been paid to adults, and the needs of older adults with autism are yet to get a real look-in.

So I was very pleased to chair the Autism and Ageing Commission which has worked with The National Autistic Society to develop the policy recommendations contained in this report. The very existence of the Commission marks a change in the attention the needs of older people with autism receives and this is to be welcomed.

The mood of the Commission was best encapsulated by Prof Francesca Happé who told us: “This is a group that doesn’t self-present and doesn’t come and seek services because of their difficulties with social interaction and communication. We absolutely owe it to them to go and find out what their needs are.”

I couldn’t agree more.

The clearest message to come from our evidence sessions is that the needs of older people with autism need to be explicitly considered by policy-makers if they are not to be disadvantaged.

I hope that this report marks a first step towards achieving this.

Baroness Greengross OBE
Background

About autism

Autism is a serious, lifelong and disabling condition that affects the way a person communicates with, and relates to, other people.

Autism is a spectrum condition which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to lead independent lives with little support, whilst others need specialist support throughout their lives. Everyone with autism has difficulties in the following three areas.

› Social interaction
  It can be harder for people with autism to recognise and understand other people’s feelings and express their own, making it difficult for them to ‘fit in’ socially. Many adults with autism are socially isolated and their family may be their only form of social contact.

› Social communication
  People with autism can find it difficult to use and understand language (both verbal and non-verbal) to different degrees. When talking to professionals, adults with autism will benefit from meetings which are set up to take account of their preferred style of communicating. They may like to have an advocate present who can help them express their needs and aspirations.

› Social imagination
  People with autism can find it hard to imagine situations outside of their own routine, and so to plan for the future, to cope with change or to manage in new and unfamiliar settings. They may also find it hard to understand and predict other people’s intentions and behaviour.

In addition, people with autism may experience over- or under-sensitivity to sounds, tastes, smells, lights or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but still have difficulties with understanding and processing language.

Throughout this report, unless otherwise specified, where we refer to autism we are referring to the entire autism spectrum, including Kanner autism, Asperger syndrome and high-functioning autism.
Background

About The National Autistic Society
The National Autistic Society (NAS) is the UK’s leading charity for people affected by autism. We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children. Today we have 20,000 members and over 100 branches, and provide a wide range of advice, information and support as well as specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism.

About Push for Action
In May 2013 the NAS launched its *Push for Action* campaign in England to turn the Autism Act into action and ensure all adults with autism get the everyday support they need. The campaign aims to get central and local government to fulfil the commitments arising from the Autism Act 2009. This new report is linked to the *Push for Action* campaign. It highlights the *Push for Action* recommendations that will most benefit older people and identifies where further action is needed, both in England and in the rest of the UK, if older adults with autism are to get the support they need.

About the Autism and Ageing Commission
In 2013 the NAS convened an informal, ad hoc 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 Commission sat for two evidence sessions in the House of Lords in March 2013 and a follow-up meeting was held in April 2013 to advise on policy recommendations.

The Commission was chaired by Baroness Greengross OBE. In addition, the following peers made up the inquiry panel, with some attending the follow-up meeting too:

- Baroness Barker
- Baroness Browning
- Baroness Eaton
- Baroness Howarth
- Baroness Jolly
- Lord Touhig
- Lord Wigley

The findings of the evidence sessions and follow-up meeting are included in this report and contributed greatly to the policy recommendations here.
Acknowledgements

Thank you to The Clothworkers’ Foundation. Without their generous support none of this work would have been possible.

Thank you to everyone who gave up their time to be involved in the interviews and focus groups on which this report is based, who shared their stories in the hope that things would be better for other people. Some names have been changed in this report to protect anonymity.

Thank you to the peers who sat on the Autism and Ageing Commission, whose expertise and dedication were invaluable, and to all the people who came to give evidence, whose knowledge and experience have been vital to this report.

Thank you also to the following NAS staff: Hannah Barnett, Sarah Lambert, Robert MacBean, Claire Meredith, Debbie Moss, Josie O’Donoghue, Ayla Özmen, Carol Povey, Shirelle Stewart, Meleri Thomas, Sue West and staff at Somerset Court.
Older adults with autism are a neglected group. They have received little attention to date in policy, research or service provision. In large part, this is because autism was only identified in the 1940s and the first generation of adults to be diagnosed in childhood are only now moving into older age. But it needs to change. This report aims to be a first step towards ensuring that policy makers address the needs of this overlooked group.

In this report, we set out the challenges facing people with autism in older age – as reported by them and by the people who support them. We also suggest how changes to central and local government policy can help to meet these challenges and so help all older adults with autism to lead the life they choose.

This report is based on interviews, focus groups and surveys with older people with autism and their families, as well as on the outcome of two parliamentary evidence sessions during which a panel of peers (the Commission) heard evidence from a variety of experts (see page 35).

It is clear that government leadership is needed. This means using the tools at governments’ disposal to encourage or require health and social care services to take steps to better meet the needs of older adults with autism. It also means spearheading work to establish how the needs of older people with autism can best be met – by issuing best practice guidance and commissioning research.

At this stage, the key message for local authorities and the local NHS is that they need to plan appropriate services for older people with autism who live in their area, and take steps to ensure that mainstream services are autism-appropriate. Data collection will be integral to the success of local planning, as will incorporating this data into local commissioning plans.

This report’s focus is policy, which means that issues we have uncovered that do not require a policy-led solution have not been addressed. This does not mean they are any less important. For example, age-related changes such as retirement can pose significant challenges for people with autism. However, issues like this may be better addressed through, for example, information provision rather than policy changes. This report is limited to the major policy-related issues raised in interviews, focus groups and the Commission evidence sessions. Additional issues may be important to other older people with autism, their families and support workers, who we did not hear from.

Finally, it is important to note that improving the support we provide children and younger adults with autism is crucial to improving the lives of future generations of older people. During its interviews, the NAS heard about numerous cases in which a lack of support in earlier life has led to hardships in older age. One interviewee told us how difficulties in communicating minor, treatable health issues to doctors in earlier life meant these have now escalated into serious and debilitating problems. Another told us that, unable to cope following the death of his mother, he was forced to give up work, resulting in a diminished pension in retirement.

Improving diagnosis, healthcare professional training and employment support for younger adults should greatly improve the situation for the next generation of older people with autism. Key to this will be the implementation of the adult autism strategy for England (Fulfilling and rewarding lives) and the statutory guidance (Implementing fulfilling and rewarding lives), and the national strategies in Northern Ireland (Autism Strategy and Action Plan), Scotland (Scottish Strategy for Autism) and Wales (Autistic Spectrum Disorder Strategic Action Plan).

Geographical extent
Most of this report’s findings are relevant to the whole of the UK. Residents of Wales and Scotland were interviewed for the report and some of the statistics that we used are from UK-wide surveys. The Commission evidence sessions and some of the background research, particularly the information on services, focused on the English policy context. As a result, the report’s recommendations focus on England. However, we recommend how the issues identified might be addressed in Northern Ireland, Scotland and Wales.
Policy Context

The Autism Act, the autism strategy and statutory guidance (England)

In the adult autism strategy, the Government committed to reviewing progress in 2013. It will hold focus groups and online engagement with people with autism as part of the review.

The strategy is intended to benefit adults with autism of all ages, but our work indicates that additional action is needed to make sure the strategy benefits older people with autism.

Our first recommendation is therefore that the Department of Health should make sure older people are represented in its autism strategy review engagement work, particularly its focus groups and online engagement.

Northern Ireland, Scotland and Wales
Strategies to improve services for people with autism of all ages are in place or being rolled out in Northern Ireland, Scotland and Wales. In Northern Ireland, this is the *Autism Strategy and Action Plan*, in Scotland the *Scottish Strategy for Autism*, and in Wales the *Autistic Spectrum Disorder Strategic Action Plan*.

In Northern Ireland, the needs of older people should be explicitly considered in the ongoing development of the Action Plans arising from the development of the Autism Strategy.

We welcome the fact that the *Scottish Strategy for Autism* explicitly recognises the need to support people with autism in older age and urge the Scottish Government to ensure that this is a reality.

The Welsh Government’s work to date is welcome and it should ensure that older people’s needs are given due consideration in the refresh of the *Autistic Spectrum Disorder Strategic Action Plan*.

Older people’s policy
The Secretary of State for Health has stated that ‘older people’ are one of his five key priorities and a number of government policies aim to improve the lives of older people. However, it is not always clear how these policies apply to older people with autism. We therefore recommend that the Department of Health issues guidance on how government policy on older people applies to people with autism. This should include guidance on dementia and end of life care policies.

NICE guideline
In 2012, in accordance with commitments in the autism strategy for England, the National Institute for Health and Care Excellence (NICE) published clinical guidelines on diagnosis and support for adults with autism. This guidance applies across England, Wales and Northern Ireland.

Care reform – England and Wales
In England, the Care Bill seeks to create a single ‘modern’ law on adult social care. Care reforms are being taken forward in Wales, through the Social Services and Well-being [Wales] Bill. These changes provide an opportunity to ensure the needs of older adults with autism are met.

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1 The Department of Health, Social Services and Public Safety has endorsed the NICE guideline on autism in adults with some caveats, which can be seen here: [http://www.dhsspsni.gov.uk/nice_cg_142_-_additional_caveats.pdf](http://www.dhsspsni.gov.uk/nice_cg_142_-_additional_caveats.pdf)
Chapter 1: Diagnosis

Getting a diagnosis can be a crucial milestone for people with autism. However, accessing and coping with diagnosis in older age poses particular challenges.

Under-diagnosis and referral for assessment

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. The National Institute for Health and Care Excellence (NICE) offered the following analysis:

“Autism was not included in psychiatric classification systems until […] 1980 […] and the diagnostic criteria for Asperger’s syndrome were only established in 1994 […] Therefore those who may meet these criteria and were children prior to this time are unlikely to have been identified. Although little is known about the healthcare needs and experiences of older people with autism, what is evident is that there is under-diagnosis in this demographic group (Brugha et al., 2011) and that there are additional barriers to diagnosis such as behavioural or medical problems (Tsakanikos et al., 2007). It is important for healthcare professionals to be aware of the signs and symptoms of autism and that they may be masked by coexisting conditions.”

The Commission heard that a lack of awareness amongst professionals working with older people, such as older age psychiatrists, contributes to under-diagnosis, and can lead to misdiagnosis, in this group. This highlights the crucial importance of training amongst healthcare professionals, discussed in Chapter 3.

In common with all adults with autism, older adults interviewed by the NAS reported lengthy waits for diagnostic assessment. The partner of one woman we spoke to had been waiting for over four years. This is unacceptable. Clear and efficient diagnostic pathways for adults are needed in each area.

The English adult autism strategy, Fulfilling and rewarding lives, and statutory guidance, Implementing fulfilling and rewarding lives, made clear that every local area in England should have a pathway to diagnosis for adults by 2013. Yet NAS research showed that just 63 out of 152 English local authorities had a pathway in place. Our Push for Action campaign, which calls for better support for adults with autism, demands that all areas have a “pathway to diagnosis”, in line with their duties in the autism strategy.

The assessment process

Diagnosing autism in older people can raise particular difficulties. The NICE guideline on diagnosing adults with autism expressed concern that:

“…particular groups, including […] older people were less likely to be identified by standard case identification tools. The review of the literature undertaken to address this question failed to find any tools that specifically addressed the needs of [this] group[…]”

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4Özmen, A. (2013). Push for Action: we need to turn the autism act into action. The National Autistic Society
They appeared to have similar concerns about assessment tools. Ideally, an autism diagnosis requires third-party information on early developmental history and face-to-face assessment. This can be problematic. Older people often struggle to provide information on their developmental history. Parents or other relatives may no longer be around to help, and documents such as school reports have frequently been lost.

Even when such information is available, the required level of detail often cannot be provided. Assessment tools have generally been developed to diagnose autism in children, when parents are likely to recall the details of their child's development. By the time people have reached older age the same level of detail is unlikely to be available.

We have heard anecdotal evidence of people being refused assessment in the absence of developmental history.

The NICE guideline on autism in adults states that a comprehensive assessment for autism should “where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development” (our emphasis). The guideline also states that during a comprehensive assessment clinicians should enquire about and assess “core autism signs and symptoms […] that have been present in childhood and continuing into adulthood; [and] early developmental history, where possible” (our emphasis).

Our interpretation of the NICE guideline is that information on developmental history is highly desirable, but not essential. Lack of such information on developmental history should not, in itself, be a reason to refuse diagnosis.

Various other factors make it more complex to diagnose older people with autism. Firstly, additional mental health problems have often developed. The Commission heard that rates of psychiatric problems, such as depression and anxiety, amongst people with autism diagnosed in adulthood, are “strikingly high”.

Secondly, older people are more likely to have adapted their behaviour in response to life experiences. For example, they may have developed sophisticated coping mechanisms which disguise their autism. In such circumstances, diagnosis may require experienced expert clinicians and this may require out-of-area referral.

CASE STUDY: TREVOR
Trevor, diagnosed in his 40s, told us about his search for someone to provide information on his early development.

“It was a bit difficult…my parents and grandparents were all dead by now. There was one aunt who is still alive. Well, two aunts who are still alive, but one has only had limited contact with me and the other one was fairly young to be an aunt. Probably didn’t know a great deal about my childhood… [My brother and his wife] found a contact at the church that we were born into and we spoke to them. They had been pretty close to Mum and Dad back when I was small and remembered a few things about my background. But it was difficult.”

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7Ibid, paragraph 5.4.5, page 134
8The Diagnostic Interview for Social and Communication Disorders (DISCO) is a notable exception. DISCO has been designed and evaluated to assist in the diagnosis of individuals with a query of an autism spectrum disorder of all ages.
10Ibid, paragraph 1.2.7
Chapter 1: Diagnosis

The impact of diagnosis

In many cases, those older adults who do have a diagnosis of autism will not have received their diagnosis until relatively late in life. One NAS survey found that 71% of respondents over 55 had received their diagnosis in the past decade. NAS interviewees diagnosed later in life reported that the diagnosis was immensely valuable, with many saying that it enabled them to understand themselves fully for the first time. A number of people the NAS spoke to said they felt counselling would help them come to terms with their past, and 45% of people over 45 who responded to an NAS survey said they would like counselling but were not receiving it. In developing post-diagnostic support, commissioners should ensure that autism-trained counsellors are available at a local level.

Without a diagnosis, it can be difficult to identify appropriate support for people with autism across the spectrum. Even where adults with autism are receiving support, if this has been as a result of a co-occurring learning disability, the support can break down if the autism is not also identified and properly supported.

Despite the positive impact of diagnosis, many interview participants revealed that they struggled to come to terms with their earlier lives before they received their diagnosis, and the opportunities and experiences they had missed due to undiagnosed autism.

CASE STUDY: CHRIS
Chris, diagnosed in his early 40s.

“I admit it wasn’t an easy diagnosis because of the drive to be normal. My adaptive skills became so highly refined...Work and social relationships were always an enigma to me but if you can pull off looking normal people will take you as such...It was only because I went private and met someone who knew the tricks of concealment that I was able to get a diagnosis. I had presented myself to GPs for over 20 years.”

CASE STUDY: VIVIENNE
“I was diagnosed at 46. It was liberating, absolutely liberating. I stopped having a self-perception of someone who is mad, bad and dangerous to know, and I became someone with autism, someone who tries very hard, someone who’s intelligent, someone who always means well but who gets it wrong.”

CASE STUDY: SIMON
“Coming to terms with [autism] late in life, I think is a lot more difficult... you look back and think, ‘I’ve really wasted my life’. Knowing a bit earlier, then I could have worked around that, ...or there might have been some help, for example, when I started at Oxford and had to give that up.”

CASE STUDY: CYNTHIA
“I don’t get very much support, particularly from most friends and family. They’re slightly confused about it all... but I have been lucky to have good private counselling, which has been my main source of support. If I hadn’t been able to do that I think life could have got very difficult indeed.”

Özmen, A. (2013). Push for Action: we need to turn the autism act into action. The National Autistic Society
Ibid
Our recommendations

ENGLAND
The Department of Health should:
› use the autism strategy review to highlight how the NICE guideline should apply to older people. Any information the Department develops for local NHS bodies on diagnosing autism in adults and the NICE guideline should clarify how the guideline should be applied to older people
› fund a small-scale research project to investigate ways to overcome the challenges posed by diagnosing adults in older age.

Clinical Commissioning Groups (CCGs) should:
› ensure they are developing post-diagnostic support, including counselling from counsellors trained in autism.

NORTHERN IRELAND
› All health and social care professionals, including those working in older age specialisms, should receive autism training.
› Strong and effective pathways to diagnosis should be developed in every area, which take account of the particular difficulties of diagnosing older adults.
› Health and Social Services Trusts should ensure they are following the NICE guideline on adult diagnosis, and applying it appropriately to older people.

SCOTLAND
› Clinicians should ensure older people are not unduly disadvantaged in autism diagnosis by the requirement for developmental history.

WALES
› The Welsh Government should ensure that planned pathways are put in place for the assessment and diagnosis of older adults.
› Local Health Boards should ensure they are following the NICE guideline on adult diagnosis, and applying it appropriately to older people.
Chapter 2: Research on autism in older age

A quick review of the literature reveals the paucity of research into autism in older age.\(^{15}\)

In her evidence to the Commission Prof Francesca Happé summed up the state of knowledge of this area as “practically non-existent”. She said:

“We simply do not know what autism spectrum conditions look like in older age. We just don’t know. We don’t know whether particular sorts of physical health problems are greatly raised. We should suspect that they would be because living with stress, living with anxiety, has a proven link with, for example, heart conditions. We don’t know how best to diagnose in the very elderly, we don’t know how dementia looks overlaid on top of autism, for example. We don’t know what the potential is for new insights both into autism, and into ageing itself. If you look at the example of Down’s syndrome, where so much has been discovered, both about Alzheimer’s, and about how people with Down’s syndrome themselves age – we might expect similar insight for autism…”\(^{16}\)

This lack of knowledge has an impact on service planning and delivery. Without knowledge of how the needs of people with autism change in older age we cannot plan services or develop appropriate interventions. As one study put it:

“…The absence of studies that have investigated individuals [with autism] who are truly ageing is readily apparent… At present it is difficult to imagine that there is adequate knowledge, preparation and provision to fully support the population.”\(^{17}\)

Prof Happé told us that research priorities in this area include:

- a survey of the physical and mental health and quality of life of older adults with autism
- establishment of a population-based longitudinal study of older adults with autism, to map the trajectory of change in symptoms, cognition, and brain structure and function.

Other specialists in autism research confirmed this is the case.

Prof Happé believes that the UK would lead the world if it commissioned such research. International experts are becoming aware of the pressing need for studies on autism in older age, which the UK, with its universal healthcare provision, is well placed to conduct.

The Department of Health told the Commission that they saw their role as “removing the barriers” which prevent the needs of people with autism being met.\(^{18}\)

Lack of knowledge is a key barrier.

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\(^{16}\)Prof Francesca Happé, speaking to the Autism and Ageing Commission, 11 March 2013.


ENGLAND

The Department of Health should:

› make research funding available on ageing and autism. Priorities for this research should be for surveys of the physical and mental health and quality of life for older adults with autism, as well as the establishment of a population-based longitudinal study of older adults with autism.
Chapter 3: Health in older age

People typically experience increased health problems in older age. This poses particular difficulties for people with autism because of difficulties in recognising and communicating ill health, and in accessing treatments.

Identifying health problems

People with autism may experience and report pain differently to others. Difficulties with understanding feelings, with communication and with insight can make it hard for some people with autism to recognise when they are unwell. This becomes more pressing in older age as ill health increases.

CASE STUDY: NANCY

“I don’t experience pain in the same way as other people... I can open up the oven, pick up a cast iron casserole, stand up with it, put it on the table, and it’s only when my niece says, ‘Auntie, your hands are peeling off,’ that I think, ‘This isn’t good,’ but it’ll be another five minutes before mild discomfort becomes agony. I missed appendicitis completely and woke up in hospital with peritonitis…”

CASE STUDY: LIS

Lis’s sister has autism and spent 20 years living in a residential home from the age of 19.

“My sister doesn’t automatically communicate new information. One of my concerns as she gets older is that if she felt unwell or had health problems we would have trouble getting that diagnosed as she just doesn’t necessarily say she has a stomach ache, for example, or it might not be obvious that she is feeling discomfort.”

The Commission heard from service providers that difficulties in identifying ill health can be a major problem in supporting people with complex needs. People with the most complex needs often do not, or are unable to, verbally report pain or health difficulties. Problems are therefore difficult for staff to detect and are often identified only after staff observe changes in behaviour. However, support staff report healthcare professionals wrongly attribute manifestations of health conditions (such as challenging behaviour) to patients’ autism, ignoring support staff’s advice to the contrary.

A service provider told the Commission that difficulties in identifying ill health are compounded by users of their residential services being excluded from public health measures such as mammograms.

Dementia is particularly difficult to diagnose amongst people with complex needs because of symptom cross-over and communication difficulties, and because few clinicians are familiar with both autism and dementia. As a result, the Commission heard reports that, in some cases, diagnosis is taking years.

Some older adults with autism told the NAS that their families help them to identify when they are ill and communicate with healthcare professionals. As these family members are growing older too, this support is likely to diminish just as it is most needed.

Taken together with the fact that it is unknown whether or not autism increases the chances of developing particular conditions in older age, the above creates a strong case for annual health checks for people with autism who are over 50.

Accessing healthcare

Some older people with autism cited increasing ill health as their primary concern about ageing because healthcare settings and communication with healthcare professionals are so stressful. Increasing awareness of autism amongst healthcare professionals is key to improving people’s experiences.
What can autism-friendly health care look like?

Harry has a diagnosis of autism and learning disability. He is non-verbal. His family told the NAS:

“Harry was sent an appointment for routine scan for an abdominal aortic aneurysm – a new service for men over 64. Harry has a severe phobia of all things medical but we agreed with his GP that we should try.

We spoke to the screening nurse who was most understanding. She offered us an early morning appointment so as not to keep Harry waiting, offered to wear blouses instead of uniforms and assured us that if we didn’t manage a scan on the first visit we could come again.

We arrived to a VIP welcome. An extra room had been set aside so that Harry would not be rushed and the patience and understanding displayed by staff was beyond all expectations. However, nothing could persuade him to lie down for the scan.

To our amazement and delight they then offered Harry a home visit so that he could lie comfortably on his own sofa for the scan. The scan was carried out successfully.

However, additional steps need to be taken if older people are to benefit fully from the strategy’s commitments. The Commission heard anecdotal evidence that clinicians working in age-related specialisms often have a poor understanding of autism and that people simply do not think of autism as a condition affecting older people.

CASE STUDY: NEIL

“As I get older, I worry what is going to happen to me if I have to go into hospital… Even a visit as an outpatient to a hospital is exceedingly difficult. Without a support worker I couldn’t manage it. The sensory overload, the social demands, and the difficulty with communicating with healthcare people, are frightening and overwhelming. I’ve already refused hospital tests because of the sensory difficulties… as I get older, I can only see that getting worse…”

Autism training for health and social care professionals is a key priority in the English autism strategy. It set out how autism training enables professionals to adjust mainstream services and can increase diagnosis rates through increased awareness and thus referral.

However, NAS research outlined in the Push for Action report suggests that the provision of training is patchy and the Department of Health is yet to fulfil national commitments, such as including autism awareness training in the core curricula for doctors, nurses and other healthcare professionals.19

The Push for Action report recommendations which aim to speed up implementation of the strategy’s training commitments will be important here, in particular: the call for the Department of Health to ensure autism awareness training is included in healthcare professionals’ curricula and that autism is included in health and social care outcomes frameworks; and the call for local authorities and local health bodies to ensure training is available across health and social care.20

19Özmen, A. (2013). Push for Action: we need to turn the autism act into action. The National Autistic Society
20Ibid.
Our recommendations

ENGLAND

**The NHS Commissioning Board should:**

- consider amending the Direct Enhanced Services (DES) scheme, which rewards GP practices for offering annual health checks for people with learning disabilities, to include people over 50 with autism across the spectrum.

**The Department of Health should:**

- work with the British Geriatric Society and the Old Age Psychiatry Faculty of the Royal Society of Psychiatrists to incentivise autism training through continuing professional development
- use its review of the autism strategy to highlight that strategy implementation must benefit older people and that training healthcare professionals is key to it doing so.

NORTHERN IRELAND

- All healthcare professionals should receive autism training.
- The Government of Northern Ireland should look to provide annual health checks for people with autism over 50.

SCOTLAND

- The Royal Colleges should ensure that e-CPD training is available and promoted to clinicians working in older-age specialisms.

WALES

- The refresh of the *Autistic Spectrum Disorder Strategic Action Plan* should highlight that the plan is intended to benefit older people too and that training healthcare professionals in autism, including those working in older age specialisms, will be key to it doing so.
Chapter 4: Preparing for the future

As people with autism move into older age their needs and support networks may change. Central and local government both have a role to play in ensuring preparations have been made to deal with these changes – not least to prevent them from escalating into crises.

Reliance on families

96% of parents of people with autism responding to an NAS survey in 2012 said they were concerned about what will happen to their child when they are no longer there to support them. 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.

Families of people with autism 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 advocate if this were the case.

CASE STUDY: CLARE

Clare Beswick, whose brother has autism and a learning disability, told the Commission:

“A best interest decision was made, that Paul should live closer to me in the South East. This has proved to be a path peppered with huge obstacles and challenges... I’ve had to go to extraordinary lengths to enable Paul’s needs to be met... Without my support, advocacy, and intervention, I believe Paul would never have had the opportunity to be moved to be near us.”

Independent advocacy is crucial for people with autism, particularly those whose families are no longer able to advocate on their behalf. But advocates, including Independent Mental Capacity Advocates (IMCAs), must be trained in autism.

Older adults with autism living in the community frequently rely solely on their families for support; few older respondents to NAS surveys received statutory support. For instance, 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 family and only 8% had most support provided by professionals.

NAS surveys indicate that younger adults with autism find it easier to access services than older people. One NAS survey found that respondents aged between 40 and 64 are less likely to have local authority or health service support than younger people. Respondents aged over 65 were just as likely as younger people to have such support.

This may be because relatively few 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 respondents had had their needs assessed in the past two years, compared to younger respondents.

The support families provide

Interviews conducted by the NAS in 2013 found that families supporting older adults with autism often provide crucial ‘lower level’ support. For example, families often provide support with making phone calls, shopping, cooking, cleaning, throwing things away, washing, travelling, filling in forms, dealing with correspondence, communicating with officials and professionals and acting as a ‘social mediator’.

People report that without such support they could not go on living in their own homes as things would spiral into crisis. Yet survey results indicate that the vast majority of people with autism would prefer to continue living in their own homes.
CASE STUDY: JULIA

“If anything were to happen to my husband, well, within days I wouldn’t be eating, or I would be eating wildly inappropriately. I have serious food allergies but the local shop doesn’t store the right sort of food for me … Within weeks I would no longer be washing or leaving the house or communicating at all with the outside world, and I’d know something was very wrong, I just wouldn’t know what to do to make it any better… So I am worried, because statistically he’s going to go first. Even if I get no worse than I am at the moment, I’m not going to be able to cope, so that would probably mean not even supported living, but residential care, and that’s a dreadful prospect.”

Government have said they want older people to be able to stay in their own homes. However, we cannot rely on families to provide the support necessary for older people with autism to do so. These families will be ageing as people’s family members die or become less able to assist them, support will begin to drop away.

Kevin Hulls of the Burgess Autistic Trust, a community-based service provider, told the Commission that a number of the people they support live at home with elderly parents with little or minimal social care because local authorities perceive them as having their needs met. However, they are concerned by “the lack of preventative strategies… for when that [parental] care is not there.”

Parents and siblings also told the NAS that they would be very concerned if there was no one to ‘check up’ on their family member. Parents told us that they think it is important that there is ‘someone around’ for their son or daughter to prevent crises developing and, sometimes, because they felt their son or daughter was vulnerable to being exploited. They told the NAS they feel someone should ‘be around’ to proactively check that their son or daughter is, for example, eating, to check they’re feeling ok, and check there are no problems emerging, for example with their home or finances.

However, social isolation is high amongst older people with autism. 73% of people over 55 who responded to an NAS survey had three friends or fewer, with 65% saying that their main friends are their families or carers.

CASE STUDY: BETTY

Betty is in her 80s. Her son has Asperger syndrome. She is concerned about what will happen when she is no longer around.

“He was taking out insurances for different things, which he didn’t need, but you know, people talk you into things. It’s sorted out now but there needs to be someone around when I’m gone to keep an eye on it… He needs someone around to speak up for him.”

Filling the gap: possible solutions

NAS research has shown that some adults with autism, particularly those with Asperger syndrome, find it difficult to access the lower level, lower intensity support they need. In part this is due to the lack of understanding of autism among community care assessors, which means that the needs of adults with autism are not fairly or comprehensively assessed.
In England, the autism strategy and statutory guidance set out that specialist training should be provided to key ‘gatekeepers’, such as community care assessors.\textsuperscript{27} NAS research found that only around half of English local authorities currently have specialist training available for their staff.\textsuperscript{28} This needs to be rectified. The recommendation in our \textit{Push for Action} report that the Care Bill be amended to require training of community care assessors would undoubtedly help to do so.

In addition, a greater focus on prevention in social care, as set out in the Care Bill in England, may help to increase the availability of the lower level support that some older people with autism need. However, it is currently unlikely that these services would include the ‘checking up’ role parents want to see.

In his evidence to the Commission, Chris Mitchell, of the Nottinghamshire Adults with Asperger’s Team, proposed that communities establish informal networks of support for older people with autism, such as volunteers, members of a dedicated ‘circle of support’, buddy schemes, luncheon clubs and drop-in services.

NAS interviews indicate that those embedded in community networks, particularly religious community networks, are better placed to meet the challenges older age brings. For example, one older gentleman with autism we spoke to receives significant support from groups established to support his community, including help with the house and outreach work, activities and day services. For others, religious organisations and the community they provide offer less formal support but nevertheless play a crucial role. For example, one man told us that:

“There are one or two people that I can phone up, I used to phone up quite a lot when I was getting stressed. People from my church…”

Volunteer networks may be able to replicate the role of such communities. The NAS is currently developing a small-scale volunteer network that would involve volunteers ‘checking up’ on older adults with autism. Other volunteer-led support models, such as the ‘circle of support’ model, could greatly benefit older adults too, though established models may need to be adapted to enable volunteers to take over caring responsibilities gradually from the parents of older adults.

\textbf{Planning for transition in services}

Particular challenges and questions are raised as people with autism in receipt of services move into older age.

The Commission heard evidence from providers of residential services for people with autism with complex needs, who said their services face challenges in adapting to older residents’ changing needs.

For example, ill health amongst residents may require additional staffing time but this is difficult to fund due to conflict between health and social care over funding. This problem becomes more pressing in older age as health problems may increase.

Hannah Barnett of the NAS told the Commission:

“A resident broke her arm recently and she didn’t like having the cast on, so kept pulling it off. She required one-to-one support to keep that in place and to ensure that it healed. There was a distinct disagreement between the health and social care providers about who was going to pay for that additional funding. In the end it was soaked up by the service provider.”

\textsuperscript{27}Department of Health (2010), \textit{Fulfilling and rewarding lives: the strategy for adults with autism in England}, and Department of Health (2010). \textit{Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy}. Department of Health

\textsuperscript{28}Özmen, A. (2013), \textit{Push for Action: we need to turn the autism act into action}. The National Autistic Society
Providers also reported difficulty in securing age-related adaptations to their services. For example, Hannah Barnett of the NAS told the Commission they waited over a year for an occupational therapist to visit a residential service to advise on the age-related adaptations that needed to be made. She also said that there was no obvious route to fund training to ‘up-skill’ staff and so enable them to support older people who use NAS services.

Providers also reported that they believe funders need to recognise that people’s needs change in older age and to factor this into their approach. Kevin Hulls told the Commission:

“One of the issues we’ve faced over the last couple of years is the increase in outcome-focused contracts which is really good because we want to help our service users to achieve more. What we’ve found is that there is sometimes a lack of understanding on the part of the people that come in and audit our services or look at our care plans, that people might choose to slow down or do less in older age, or they might not be able to – and they’re quite happy with that. I mean, we’ve got a service user who at 65 just decided to retire. He didn’t want to go to the day centre anymore, he wanted to retire, but as a provider you become pressurised to try and fill up people’s time, and that’s not always fair on the person.”

The Commission heard evidence that local authorities are not planning adequately for the changing needs of people with more complex needs in older age, or for any necessary transition into services better equipped to support older people. People with autism can find change very difficult to cope with so it is important that any changes are adequately planned. For example, Hannah Barnett told the Commission that:

“When a man with Parkinson’s disease who we support in our services needed to move on and we wanted to look for new services for him, we couldn’t engage the local authority. Eventually, they did send somebody down and tried to move him within about three days of actually doing an assessment of him, with no look at his transition or anything like that.”

These problems could be partly addressed through ongoing and regularly updated person-centred plans, which should always be looking at changing needs. As individuals get older, specific attention should be paid to changing health needs and the adaptations that need to be made as a result. Local authorities should work closely with providers, particularly to ensure adequate funding for adaptations and on ensuring carefully-planned transitions to more appropriate settings. The Department of Health should take a lead on collecting and disseminating good practice guidance for local authorities, particularly on transitioning to new providers.
ENGLAND
Local authorities should:
› consider volunteer-led models to support older people with autism in developing local commissioning plans, and fund such services to meet need.

The Department of Health should:
› issue examples of best practice for local authorities on planning the transition into older age for people with autism in receipt of services
› amend the Care Bill to include a general right to independent advocacy. People with autism must be included as one of the groups to whom this right applies
› amend the Care Bill to require services to be provided to people whose needs would be assessed at equivalent to ‘moderate’ under current Fair Access to Services (FACS) criteria in secondary legislation.

NORTHERN IRELAND
› In the ongoing reforms of health and social care special attention needs to be given to the need for preventative services for older people with autism.

SCOTLAND
› In the reforms to integrate health and social care special attention needs to be given to the need for preventative services for older people with autism.
› As local autism strategies are developed the availability of, and need for, independent advocacy services should be mapped across all services that people with autism need to access and that they use.

WALES
The Social Services and Well-Being [Wales] Bill:
› should place a duty on local authorities and health boards to provide advocacy
› should provide guidance for local authorities to help them deliver assessments more effectively for people with autism
› places a duty on local authorities and Health Boards to provide a range and level of preventative services which is welcome, but these services should be adequately resourced.
Chapter 5: Ensuring appropriate services and support are available

It is important that services are available that meet the needs of older people with autism. This means making reasonable adjustments to mainstream older people’s services, enabling autism services to adapt to the needs of older people and, where necessary, commissioning specific services. Central and local government both have a role to play.

**Autism-friendly mainstream services**

Ensuring mainstream older people’s services are accessible to people with autism is essential if older people are to benefit from the autism strategy for England’s ambition that adults with autism should be able to “depend on mainstream public services to treat them fairly as individuals.”

NAS interviews found that a number of older people with autism are concerned about, or dislike using, older people’s services. They feel such services do not or may not understand their needs, and so do not or would not make reasonable adjustments. As a result, they struggle, or believe they would struggle, with the sensory and social environments of such services.

**CASE STUDY: NEIL**

“I can’t manage to live independently on my own. So, if I didn’t have the support…I’d have to go into some sort of care home or something, which would probably finish me off, [because of the] sensory overload – lights and noise.”

**CASE STUDY: CHRISTOPHER**

“I can’t communicate very well. [If there is a problem] some autistic people agree to do things that they don’t have to do like give people money when they don’t owe them money and some autistic people scream their way out of it.”

**CASE STUDY: LILLIAN**

“As a society the very young and the very old get more than their fair share of physical contact, because neurotypicals want to pat them. I saw some excellent carers, had them working under me, who, when they spoke to someone who was a bit vague, the hand would go down and they’d say, ‘How are you today Mrs Brown?’ ‘All right, yes,’ and they’d be hand-holding her. That’s absolutely right for a neurotypical, it’s absolutely wrong for an autistic person. …The horror of unwanted physical contact with people…you know they’re doing this to be nice, but their fingers feel like ice on me. That’s horrible, and so stressful. Some of the most stressful and distressing things neurotypicals do is hug.”

Lack of autism awareness amongst older people’s services is worrying for individuals. It also means that staff are ill-equipped to know how to support an adult with autism. For example, the NAS heard concerns that a lack of autism awareness would lead to inappropriate support which, in some cases, could lead to challenging behaviour.

CASE STUDY: NIGEL

Nigel is the father of an older man with Asperger syndrome.

“I think what I’d be afraid of is that the same sort of thing would happen to my son in older people’s services as happened when he was looking for hostels, and that is he’d be moved on from one home to another because he’d blot his copy-book in one way or another in different ones…”

The NAS made an information request to 15 English local authorities to determine to what extent staff in older people’s services are trained in autism. The results were patchy: some local authorities had not trained any staff in older people’s services in autism, others had trained a significant number. However, it was not always clear how these figures were being calculated.

None of the local authorities we asked required commissioned providers of older people’s services to train their staff in autism. However, some local authorities pointed out that they did require providers’ staff to be trained to meet the needs of clients.

The NICE clinical guideline on adults with autism recommends that each local area sets up an autism team. Part of the role of such a team is to support mainstream services to make adjustments for people with autism. The Commission heard that this is the best way to ensure older people’s services are autism-friendly too.

Dr Ian Ensum, of the Bristol Autism Spectrum Services, told the Commission:

“There is a huge architecture out there to support people in old age. The trouble with that architecture is, it doesn’t know what it’s doing with autism. …So, the key is to set up autism teams… Those autism teams need to talk to old people services… the job of these specialist teams for me, primarily, is to train and supervise and make mainstream services care better for people with autism, not to do the care themselves…”

To ensure people with autism are receiving high-quality care and support in mainstream older people’s services, it is important that inspectors of these services are trained in autism. If they are not they will not be able to assess the propriety of care provided to people with autism.

Age-appropriate autism services

For people with more complex needs, the Commission heard evidence that difficulties in adapting services, lack of staff knowledge on managing age-related conditions and funding battles between health and social care make it difficult for autism-specific services to continue to support people in older age.

Service adaptations and funding battles between health and social care are discussed in Chapter 4 of this report. We recognise that, in England, the Health and Social Care Act and Care Bill aim to integrate health and social care services. We urge the government to consult directly with service providers to determine whether or not these measures are successful.

Residential services for people with autism with complex needs may not be registered to provide nursing care. If the people they support require long-term nursing care in older age, such services could not therefore provide it.

Though service providers find it difficult to support some people with complex needs in older age, it was highlighted to the Commission that there is a lack of suitable alternative provision. For example, generic older people’s services may not have skills or funding to support people with more complex needs.
Kevin Hulls told the Commission about the difficulties the Burgess Autistic Trust had in finding alternative accommodation for a man using their service who had been diagnosed with dementia.

“Unfortunately, providers that are specialists in dementia care, or specialists in supporting people in older age, weren’t able to meet his needs. He needed a lot of one-to-one care, whereas a lot of the service that he was referred to had a staff ratio of something like 1:7 – that was about the best ratio. So, there wasn’t really an ideal service for him to move into.”

What is suitable accommodation for older people with autism with complex needs?

Clare Beswick, whose brother has autism, explained to the Commission how his needs have changed as he has aged and what this means for his accommodation needs.

“My brother lives in residential care. As he has aged, his needs have changed. He craves a much quieter environment in tune with his sensory needs. He lives in almost total isolation, in a group of 16 adults, with whom he was previously very happy, but as he has aged, his needs have changed significantly. His world is just getting smaller and smaller.

Our solution is to move Paul, to create a new care home for three adults. One of these new places will be Paul’s. It’s an ordinary bungalow, on an ordinary street, for three adults with autism, which will have the warmth of a family on the inside, but be a very carefully planned environment to enable it to be a home where he’s able to live the life he chooses. We’re creating an environment that can be adapted to meet Paul’s needs as he ages.

Like many people with autism and severe learning difficulties, Paul has significant epilepsy. If his medical needs change, or he needs more nursing care, then this can hopefully be provided in this new home in just the same way as we would hope to live out our lives at home with medical support. We’re trying to truly create a home for life.”

Commissioning appropriate services

Specialist provision may be needed by older adults with autism across the spectrum. However, for specialist provision to be made available, the needs of older people with autism must be placed firmly on commissioners’ radars. The Commission heard evidence that this is not currently the case. Dr Ian Ensum, of the Bristol Autism Spectrum Services, said:

“… the needs of this older group are on no-one’s agenda, to be honest... this group aren’t mentioned explicitly in any of the guidance, and if you’re not mentioned explicitly and if there is not a target attached to it, it won’t happen.... it’s nowhere near any commissioner’s radar. Commissioners are not thinking at all about the needs of older adults with autism, in my experience, and I talk to quite a lot of commissioners.”

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). However, 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.
In response to the information request, some local authorities said they did not collect any data on the number of older people with autism in their area. Others said they did, but this generally appeared to be data on the number of older clients with autism that they supported, rather than the number across the population as a whole. Yet the English autism strategy statutory guidance advises local authorities to collect data on the total population of older people with autism in their area. Collecting this data in this way will help local authorities plan for how services need to be adjusted in the future. Collecting data on the number of people with autism in receipt of services will also help to plan for adjustments to services. To achieve data collection on people with autism in receipt of services, the NAS *Push for Action* report recommends that the Department of Health adjust the standard equality classification to include new autism classifications.30

30Özmen, A. (2013). *Push for Action: we need to turn the autism act into action*. The National Autistic Society
Our recommendations

**ENGLAND**

All local authorities and local NHS bodies should:
- ensure staff working in older people’s services are trained in autism. Contracts with older people’s service providers should require that staff be trained in autism. This is in line with the Autism Act statutory guidance which sets out that all staff should be trained.
- gather information on the numbers of people over 65 with autism in the local area, as recommended by the statutory guidance, and include these figures in JSNAs.

Local authorities should:
- follow the NICE guideline on autism in adults.

The Department of Health should:
- highlight the importance of local authorities training older people’s staff in autism, in its review of the autism strategy.
- remind local authorities of their duty to collect data on the numbers of people over 65 with autism in its review of the autism strategy, and should recommend that these figures are included in JSNAs.
- amend Care Bill to require local authorities to follow NICE guidelines in exercising their ‘duty of prevention’.

The Care Quality Commission (CQC) should:
- ensure that all inspectors receive basic autism training.

**NORTHERN IRELAND**

The relevant Action Plans, arising from the Autism Strategy, should recommend that Health and Social Care Trusts collect data on the number of people with autism aged over 65 in their area and include this figure in service planning.

All health and social care professionals, including those working in older people’s services, should receive autism training.

**SCOTLAND**

Local authorities should:
- ensure the needs of older people are considered when mapping local need and making local plans, and local strategies must address the needs of older people with autism.
- train staff working in older people’s services in autism.
- ensure all community care assessors are trained in autism.

Health Boards should:
- ensure that autism is included in all equality and diversity training.

**WALES**

- Staff across local authorities and local health boards, including those working in older people’s services, need to be trained in autism if the needs of older adults with autism are to be met.
Conclusion

This report has found that older people with autism face significant challenges. Some of these challenges are specific to autism in older age – for example, the need for research funding and for autism awareness training amongst staff in older people’s services. Some of these challenges are common to adults with autism across the age ranges but become more pressing in older age – for example, the need for training amongst healthcare professionals and the need to combat social isolation.

The solutions we propose are not complex, nor are they unduly costly. Often they constitute little more than putting older people with autism ‘on the agenda’, thereby ensuring that they benefit from existing policies and that their needs are considered. In England, making sure the adult autism strategy benefits older people is the most obvious example – though they will also benefit from rapid implementation of the strategy in general, as recommended by our Push for Action report.

The autism strategies in Northern Ireland, Scotland and Wales must benefit older people too.

However, we have also identified a need for the Department of Health to lead on new initiatives for this group, such as best practice transition guidance and investment in research.

We intend this report to be a first step towards meeting the needs of older adults with autism. We look forward to working with the Department of Health, the devolved governments, local authorities and other bodies to take our recommendations forward.
ENGLAND

The Department of Health, local authorities, local NHS and other bodies should take forward the NAS Push for Action recommendations.

The Department of Health should:

› issue guidance on how government policy on older people applies to people with autism
› fund a small-scale research project to investigate ways to overcome the challenges posed by diagnosing adults in older age
› clarify how the NICE guidelines should be applied to older people in any information it develops for local NHS bodies on diagnosing autism in adults
› make research funding available for ageing and autism
› work with the British Geriatric Society and the Old Age Psychiatry Faculty of the Royal Society of Psychiatrists to incentivise autism training through continuing professional development
› issue examples of best practice for local authorities on planning the transition into older age for people with autism who are in receipt of services.
› amend the Care Bill to include:
   – a general right to independent advocacy. People with autism must be included as one of the groups to whom this right applies
   – a requirement that local authorities follow NICE guidelines in exercising their ‘duty of prevention’
   – a requirement, in secondary legislation, that people whose needs would be assessed at equivalent to ‘moderate’ under current Fair Access to Services (FACS) criteria, must be eligible for services.

In its review of the autism strategy, the Department of Health should:

› consult with older people with autism
› highlight how the NICE guideline should apply to older people
› highlight that strategy implementation must benefit older people and that training healthcare professionals and older people’s services are key to it doing so
› remind local authorities of their duty to collect data on the number of people over 65 with autism and recommend that these figures are included in Joint Strategic Needs Assessments (JSNAs).

Local authorities and Clinical Commissioning Groups (CCGs) should:

› train staff working in older people’s services in autism, and include training in autism as a contractual requirement for older people’s service providers
› follow the NICE guideline on autism in adults
› consider volunteer-led models to support older people with autism in developing local commissioning plans, and fund such services to meet need
› gather information on the numbers of people over 65 with autism in the local area, as recommended by the autism act statutory guidance, and include these figures in JSNAs
› ensure they are developing post-diagnostic support, including counselling from counsellors trained in autism.
The NHS Commissioning Board should:
- consider amending the Direct Enhanced Services (DES) scheme which rewards GP practices for offering annual health checks for people with learning disabilities, to include people over 50 with autism across the spectrum.

The Care Quality Commission (CQC) should:
- provide basic autism training to all its inspectors.
NORTHERN IRELAND

› The needs of older people should be explicitly considered in the ongoing development of the Action Plans arising from the development of the Autism Strategy.
› All health and social care professionals, including those working in older age specialisms, and older people’s services, should receive autism training.
› Strong and effective pathways to diagnosis should be developed in every area, which take account of the particular difficulties of diagnosing older adults.
› Health and Social Services Trusts should ensure they are following the NICE guideline on adult diagnosis, and applying it appropriately to older people.
› The Government of Northern Ireland should look to provide annual health checks for people with autism over 50.
› In the ongoing reforms of health and social care special attention needs to be given to the need for preventative services for older people with autism.
› The relevant Action Plans, arising from the Autism Strategy, should recommend that health and social care trusts collect data on the number of people with autism aged over 65 in their area and include this figure in service planning.

SCOTLAND

› The Scottish Government should ensure that its welcome recognition in the Scottish Strategy for Autism of the need of older people with autism for support becomes a reality.
› Clinicians should ensure older people are not unduly disadvantaged in autism diagnosis by the requirement for developmental history.
› The Royal Colleges should ensure that e-CPD training is available and promoted to clinicians working in older-age specialisms.
› In the reforms to integrate health and social care, special attention needs to be given to the need for preventative services for older people with autism.
› As local autism strategies are developed the availability of, and need for, independent advocacy services should be mapped across all services that people with autism need to access and that they use.
› Local authorities should:
  – ensure the needs of older people are considered when mapping local need and making local plans, and local strategies must address the needs of older people with autism
  – train staff working in older people’s services in autism
  – ensure all community care assessors are trained in autism.
› Health Boards should ensure that autism is included in all equality and diversity training.
WALES

➢ The Welsh Government should:
  – ensure that older people’s needs are given due consideration in the refresh of the *Autistic Spectrum Disorder Strategic Action Plan*
  – ensure that planned pathways are put in place for the assessment and diagnosis of older adults
  – highlight in its refresh of the *Autistic Spectrum Disorder Strategic Action Plan* that it is intended to benefit older people too, and that training healthcare professionals in autism, including those working in older age specialisms, will be key to it doing so.

➢ The Social Services and Well-Being [Wales] Bill:
  – should place a duty on local authorities and health boards to provide advocacy
  – should provide guidance for local authorities to help them deliver assessments more effectively for people with autism
  – places a duty on local authorities and Health Boards to provide a range and level of preventative services, which is welcome, but these services should be adequately resourced.

➢ Local Health Boards should ensure they are following the NICE guideline on adult diagnosis, and applying it appropriately to older people.

➢ Staff across local authorities and local health boards, including those working in older people’s services, need to be trained in autism if the needs of older adults with autism are to be met.
Glossary and abbreviations

**Autism and Ageing Commission** – see page 6.


**Autism Strategy and Action Plan (Northern Ireland)** – the strategy in Northern Ireland to improve support and services for people with autism in Northern Ireland, arising from the Autism Act (Northern Ireland) 2011.

**Autistic Spectrum Disorder Strategic Action Plan for Wales** – the Welsh Government’s plan to drive improvements in the commissioning and delivery of services for children, young people and adults with autism and their families and carers.

**Care Bill** – a bill to change care services in England (see page 9).

**Clinical Commissioning Groups (CCGs)** – groups of local GPs and other healthcare professionals who buy healthcare services for a given area.

**Commission** – see Autism and Ageing Commission (above).

**Care Quality Commission (CQC)** – the care regulator in England.


**Implementing fulfilling and rewarding lives: statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy** – published as a result of the Autism Act 2009, this put legal duties on local authorities to improve services for people with autism.

**JSNA** – Joint Strategic Needs Assessment. This is used by local authorities and the local NHS to analyse their populations’ health and care needs and commission services.

**NAS** – The National Autistic Society.

**NICE** – the National Institute for Health and Care Excellence. NICE produces guidance on health and social care services.

**NICE guideline** – guidance on how health and care services should design services for adults with autism (see page 9).

**Push for Action** – the NAS’ campaign around the autism strategy review (see page 6).

**Scottish Strategy for Autism** – the Scottish Government’s strategy to ensure that progress is made across Scotland in delivering quality services for people with autism and their families.

**Statutory guidance** – see *Implementing fulfilling and rewarding lives*, above.
Methodology

This report is based on findings from:

› Surveys:

› Focus groups:
In January 2013 the NAS conducted two focus groups with a total of 16 people, all older people with autism and their families.

› Interviews:
In February 2013 the NAS conducted semi-structured interviews with 24 people over 50 with autism, and their families.

› Information requests:
The NAS has put in requests for information to 15 local authorities in England on service provision for older people with autism. Some of these requests were made as freedom of information (FOI) requests. This is a 10% sample of local authorities in England.

› The Autism and Ageing Commission heard evidence from:
  – Tom Gentry, Policy Advisor (Health Services), Age UK
  – Carol Povey, Centre for Autism Director, The National Autistic Society
  – Prof Francesca Happé, Professor of Cognitive Neuroscience, MRC Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, King’s College London
  – Neville Bland, an older man with autism
  – Clare Beswick, sister of an older man with autism
  – Michael Baron, father of an older man with autism and NAS co-founder
  – Hannah Barnett, Nominated Individual, NAS
  – Kevin Hulls, Director of Operations (Adult Services), Burgess Autistic Trust
  – Dr Ian Ensum, Clinical Psychologist, Bristol Autism Spectrum Services
  – Chris Mitchell, Team Manager, Nottinghamshire Adults with Aspergers Team
  – Catriona MacKean, Older People’s Policy Hub, Department of Health
  – Stephanie Somerville, NHS Policy and Strategy Unit, Department of Health
  – Michael Swaffield, Autism Policy Lead, Department of Health
We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.7 million people whose lives are touched by autism every single day. Despite this, autism is still relatively unknown and misunderstood. This means that many people don’t get the level of help, support and understanding they need. Together, we are going to change this.

From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

We rely on donations to enable us to fund campaigns, such as this one, to bring about positive change.

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