Building

HAPPIER HEALTHIER LONGER

Lives

Briefings to improve autism policy and research

AUTISTICA
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We share a vision with the NHS: to ensure all autistic people can live longer, healthier, happier lives. We share an overarching objective with the Department for Health and Social Care: to close the gap in life expectancy between autistic people and the rest of the population.

This report is about how we can meet that objective and realise that vision. To deliver effective change, we must get much better at listening to autistic people and their families, finding out what works through rigorous research and data collection, and working together to accelerate the adoption of evidence-based solutions.

Listen to autistic people and their families
Autism policy, services and research should focus on the issues that have the biggest impact on autistic people’s lives. Too often, they do not.

Every briefing in this report was written with autistic people, about topics repeatedly identified as priorities by autistic people and their families. These issues should already be at the heart of national strategies and programmes to improve autistic people’s outcomes. Instead, some of these topics have never been mentioned in policy discussions.

Find out what works
The history of autism is littered with actions, well-intentioned and not, that failed to improve autistic people’s lives. Some failed by not actively identifying and removing biases from their plans; others failed by assuming a few people’s experiences were representative of all; many failed by neglecting to systematically measure whether their approach was safe and effective.

Good quality research guards against these failings. While the evidence it generates is fallible, good science helps us know how confident we should be about why we think something is happening and what could work to change it.

Every briefing in this report focuses on a topic with new or emerging evidence to improve policy and services. Every briefing also highlights the most pressing gaps in our knowledge: questions that need answering to address those issues effectively. We cannot afford to continue guessing what will reduce the inequalities facing autistic people. The cost in lives is too great.

Working together
It’s easy to demand that someone else fixes problems but much harder to work with them to do it. Every briefing in this report focuses on issues that public bodies can change, with recommendations for multiple organisations. Every problem in this report also needs expertise from across the scientific, service, carer and autistic communities to tackle effectively.

At Autistica, we will continue working with civil servants, service providers, researchers, autistic people and their families to find effective ways of tackling these community priorities. To accelerate progress towards longer, healthier, happier lives, we need others to join us.
**Where does our community want change?**

1. Online consultation developed around Autistica and the James Lind Alliance's priority setting exercise from 2016.

2. Autistic reviewers advised on making the consultation clear and accessible.

3. 426 autistic people anonymously shared their views through the consultation.

4. 172 relatives, carers and supporters completed a consultation on behalf of autistic people who could not advocate for themselves in this format.

**What should we focus on?**

5. A reference group of autistic people with journalistic, research or policy experience prioritised themes from the consultation where there was

   - clear community priority
   - sufficient evidence for making recommendations
   - realistic chances to influence policy on that theme
   - something the Government could change about it

**Writing and publishing**

6. Autistica teams prepared draft briefings using rapid searches of scientific publications and Autistica's collaborative workshop findings.

7. Two or three autistic people with lived experience of that topic reviewed each briefing and recommended edits.

8. Leading academic and clinical experts in that topic reviewed each briefing and recommended edits.

9. Briefings published February - June 2019 and sent to national decision makers.
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Paying people fairly

Our experts by experience deserve to be recognised. Every autistic person and family member who gave up their time to review, feedback or advise on these briefings was offered a payment in line with the NIHR’s INVOLVE guidelines.
Autistica Action Briefing: Eating Disorders


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about eating disorders in the autistic community. It was developed in collaboration with leading researchers and autistic people with experience of eating problems as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, NICE, commissioners, services and public research funders to act on this information. The evidence about eating disorders in the autistic community has moved on; services and policies aimed to tackle them must now do so as well.

“I’m just so heavy with my peers and friends dying… I can think of 3 friends I suspect will die this year and that is just people I know. I know of others just allowed to exist at weights that absolutely will mean they die in 5-10 years and this is just accepted because they have ASD”

What we know

- Approximately 1 in 5 women with anorexia in eating disorder services are autistic.2,3,4
- Anorexia has the highest mortality rate of any mental illness. Other eating disorders also significantly increase people’s risk of dying early.5
- Autistic people with anorexia face worse outcomes than their non-autistic peers, with reduced levels of recovery and more persistent difficulties with their wider mental health, social skills and employment.6,7,8
- Anorexia assessments and treatments will need to be significantly adapted for some autistic patients. Factors typically associated with anorexia, like the thin ideal or fat-phobia, may be less common or significant for autistic people who develop eating disorders, according to preliminary evidence and accounts from lived experience.9,10,11,12

What we need to find out

“Staff in eating disorder units don’t have enough understanding of autism or sensory issues it can cause. They seemed constantly frustrated with me. I felt like a nuisance.”1

Research is beginning to explore how anorexia and other eating disorders can differ for autistic people.13,14,15 It is important for autistic and non-autistic people that more studies identify whether participants are autistic, so they don’t make misleading conclusions about the effectiveness of eating disorder treatments for everyone. However, to make lasting improvements to care, we need to understand more about:

- How common other eating disorders like bulimia,16 binge eating and Avoidant/Restrictive Food Intake Disorder (ARFID)17 are amongst autistic people? At present, much of what we know about autism and eating disorders focuses on anorexia.
- What early signs could indicate risk of eating disorders in autistic people, especially young people?
- How should eating disorder assessments be adapted for autistic people to identify what is causing or exacerbating their difficulty eating?10
- What adaptations would make eating disorder treatments more effective amongst autistic people and whether new interventions would be effective?11
- How can inpatient eating disorder services be made more appropriate and supportive for autistic people?

“I almost died from anorexia at university. Had I been diagnosed with ASD prior to/during anorexia I would have recovered more quickly. The support I received did not help me at all.”1

“There appears to be no service to address my son’s serious binge eating and no one with an understanding of the low mood, sensory and reward issues surrounding it.”1

“I was almost 18 when I was diagnosed with anorexia but had no idea it was something that people with ASD also get.”1
We know a lot more about eating disorders and autism now than we did when the Autism Act (2009) or Think Autism Strategy (2014) were published. The Government recently made reducing early death the primary aim of the Autism Strategy, and have now launched a review of the Strategy for the future.

The Department of Health and Social Care should ensure that tackling eating disorders become a “priority challenge for action”, as part of a wider theme on reducing morbidity and early death.

A significant number of the people health professionals in eating disorder services will see are autistic. Despite this, the current NICE guidelines on eating disorders do not reference autism or prepare clinicians for any of the adaptations that may be required when assessing and treating autistic patients.

NICE should prioritise a review of NG69 to ensure it reflects the latest evidence on autism and eating disorders.

The NHS Long Term Plan highlights that “research-active’ hospitals have lower mortality rates” and prioritises action to reduce preventable deaths amongst autistic people. Disturbingly few clinical innovations for autistic people have been tested in NHS eating disorder services, even though they represent one of the groups at highest risks of dying early.

NHS England and the National Institute for Health Research should support all eating disorder services to become actively involved in clinical research to improve outcomes for autistic and non-autistic people. Research funders should prioritise further research into eating disorders in autism, informed by the priorities and input of autistic people and their supporters.

Eating disorder services are a setting where undiagnosed autistic people, particularly women and girls, can often present in crisis for the first time. Identifying whether patients have autistic traits could help services build a more holistic picture of those people’s needs, especially for those who repeatedly present to services or whose eating disorders appear to be severe and enduring (SEED).

NHS England should consider auditing all identified autistic people with eating disorders in inpatient settings to establish whether there were missed opportunities to intervene earlier, had autism been considered.

The Long Term Plan committed to developing and testing support packages for children diagnosed with neurodevelopmental conditions. Families of autistic people should be supported with new, evidence-based information on eating disorders and autism.

NHS England, research funders and charities should work together to ensure support packages include evidence-based advice on preventing and managing eating difficulties across the lifespan, including at points of transition.
Autistica Action Briefing:
Suicide Prevention

March 2019

Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about suicide in the autistic community. It was developed in collaboration with leading researchers, autistic people and bereaved family members as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, local authorities, services and public research funders to act on this information. The evidence about suicide in the autistic community has evolved rapidly in recent years; prevention efforts must now do so as well.

"You go to the professionals thinking these people have trained for years and years and years and they will know. Someone will know… Charlotte died on 25th January 2016, on her own, locked in her room, mobile phone switched off."  

What we know

- **A disproportionate number of people who die by suicide are autistic.** Ongoing research suggests that up to 11% of people who die by suicide in the UK may be autistic, even though only 1% of the population is on the spectrum. Those UK numbers are preliminary but fall within the range found by a Swedish population-level study and are supported by a rapidly growing international evidence base around suicidality and autism.

- **Suicide is a leading cause of early death within the autistic community.** Autistic people are substantially more likely to consider, attempt, and die by suicide than other groups. In 2018, NICE guidance on suicide prevention recognised autistic people as being among those at highest risk.

- **Autistic women are markedly more likely to die by suicide than non-autistic women.** It appears that an even greater proportion of women who die by suicide are autistic, compared to men.

- **Young autistic people with suicidal thoughts have been denied access to CAMHS.** Some overstretched services are forced to use risk assessment tools to determine who to support with limited capacity. This practice is explicitly criticised in NICE guidelines and is particularly dangerous for autistic children, especially girls, whose suicide risk is even less likely to be predicted by those tools. One small study found that autistic children are 28 times more likely to consider suicide than their non-autistic peers.

- **Factors known to increase people’s risk of suicide are more common in the autistic community,** including social isolation, unemployment, trauma, abuse and other social and biological factors that increase the likelihood of mental health problems. However, autistic people are still more likely to have suicidal thoughts in studies where both they and non-autistic people have the same rates of these risk factors. It’s also likely that autistic people face other issues that make them more likely to consider ending their own lives.

- **Autistic people struggle to access appropriate support for mental health problems or suicidal thoughts.** Some suicide prevention organisations are now exploring ways to make their services more accessible to autistic people.

"I was discharged from adult mental health services on two occasions while suicidal. On one of those occasions I was discharged directly after a suicide attempt. The reasoning was that the services didn’t feel equipped to offer psychological support to me due to my ASD."
Mental health is the autism community’s top priority for research, yet research into autism and suicidality remains underdeveloped. This represents failure to listen to autistic people and families and lack of strategic direction within autism science.

Autistica, the International Society for Autism Research and the James Lind Alliance are supporting researchers from the Universities of Nottingham, Newcastle and Coventry to work with the autistic community in identifying the next steps for research. Their recommendations are due in 2019 and should become the basis of an international collaboration to prevent suicides in the autistic community. Priorities will likely include:

- What adjustments help autistic people at risk of suicide access support when they are at crisis point?
- How does social camouflaging influence suicidality amongst autistic people?
- Which life events and environmental, behavioural or biological risk factors affect the onset of mental health problems or suicidality in autistic people?
- What is the developmental trajectory of suicidal thoughts and behaviours in autistic people?
- Why are autistic women so much more likely to die by suicide than non-autistic women? Do the methods used for suicide attempts differ between these groups?
- Does help-seeking behaviour differ between autistic people and non-autistic people?

What we need to find out

“With the words ‘help me’ screaming in my head, I was too afraid to pick up the phone”

A connection had barely begun to be made between suicide and autism when the Autism Act (2009) and Think Autism Strategy (2014) were published. The Government recently made reducing early death the primary aim of the Autism Strategy and have now launched a review of the Strategy for the future.

To reduce early death, the Department of Health and Social Care must ensure that suicide prevention becomes a “priority challenge for action”, as part of a wider theme on reducing morbidity and mortality following their review.

We invite the Minister to join the collaboration between researchers and charities looking at research priorities in this area. Her Department and the National Institute for Health Research should consider what they can do to help close the most pressing evidence gaps around prevention.

The disparity between the demand for and funding of CAMHS is forcing services to make impossible decisions about who to support. Some services are using suicide risk assessment tools to set those access thresholds. Using these tools with such a limited evidence base is dangerous, particularly for young autistic people whose risk of suicidal behaviour is both higher and less likely to be predicted by those tools.

The Long Term Plan promises investment in specialist community teams to support autistic children and their families. Investment in those community teams must be sufficient for CAMHS to dismantle the arbitrary thresholds that prevent families from accessing support before autistic people reach a crisis.

Autistic people are almost never mentioned in local suicide prevention plans. The guidance informing local authorities about suicide prevention planning is currently being reviewed.

Public Health England should take this opportunity to update that guidance and encourage local authorities to consider the autistic community in their prevention plans.

The lack of recorded diagnoses amongst autistic adults and the manner in which suicide datasets are currently collated means they are unlikely to reliably represent the deaths of autistic people. The Health and Wellbeing Alliance are currently developing a pro-forma to support coroners in identifying relevant factors surrounding deaths by suicide.

This pro-forma should allow for recognition of an autism diagnosis in order to better record the true scale of deaths by suicide in the autistic community.
The number one research priority for autistic people, families and researchers is finding and adapting interventions to improve mental health in autistic people. Most mental health interventions are tested only with adults, and autistic children are particularly likely to be excluded. This exacerbates the knowledge gap on what works for autistic children. Key research questions include:

- What are the environmental and biological causes of anxiety disorders in autistic children, and how do these vary from non-autistic children?
- Do autistic children respond differently to mental health therapies? How does this compare to their non-autistic peers? How can we personalise therapies of autistic people?
- What clinical indicators should health professionals look for to identify mental health problems in young autistic people?
Are healthcare professionals in CAMHS confident in supporting autistic children with mental health problems? Are they confident in identifying and supporting co-occurring neurodevelopmental conditions like ADHD which may influence the treatment of these mental health problems?

What non-pharmacological mental health interventions are effective in helping autistic children and young people with learning disabilities?

The Government has announced that the review of its Autism Strategy will consider the needs of children as well as adults. Mental health problems are the community’s top research priority, as well as one of the most common and difficult challenges a young autistic person is likely to face.

Mental health problems like anxiety are the norm, not the exception for autistic children. Local CAMHS systems should therefore be prepared and resourced to support autistic children as an explicit part of the commissioning process. NHS England should work with local Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) to ensure that every area has prepared clear pathways for young autistic people to access mental health support.

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The NHS Long Term Plan includes commitments to develop support packages for autistic children throughout the diagnostic process and to provide designated keyworker support to those with the most complex needs. These programmes should focus on identifying mental health difficulties like anxiety earlier and supporting families with adjustments and coping mechanisms to prevent problems from escalating.

"When he was 8, my son would say that he didn’t see the point in living. When he was 13, he would ask if I thought he could cope in the world when he grew up. Three years later he has grown lonely, depressed and reclusive"
Autistica Action Briefing:
Adult Mental Health

Harper G, Smith E, Simonoff E, Hill I, Johnson S, Davidson I. March 2019

Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about mental health in autistic adults. It was developed in collaboration with leading researchers and autistic people with experience of the topic as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. The evidence about mental health in autistic adults has moved on; services and policies to improve mental health must now do so as well.

"If a neurotypical person was afraid to leave the house, that wouldn’t be seen as normal or okay. But if you’re autistic you should just accept that that is the way your life is going to be." ¹

What we know

- **Almost 8 in 10 autistic adults experience a mental health problem.**² Autism is not a mental health condition itself, but mental health problems are one of the most common and serious challenges experienced by people across the spectrum.

- **Up to 10% of adults in inpatient mental health settings are autistic,**³ even though only 1% of the population is on the spectrum.⁴

- **Autistic people are often unable to access community mental health support.**¹,⁵,⁶,⁷ Autistic people report being “punted” between different settings; often from mental health services that are not confident in “dealing with autism” to learning disability services which can be poorly integrated with mental health services.¹,⁵,⁷,⁸ This is a particular issue for adults without a learning disability, who can rarely access timely specialist mental health support, resulting in problems escalating until emergency or inpatient care is required.⁵,⁹,¹⁰,¹¹

- **Mental health treatment may need to be adapted for autistic people.** Healthcare professionals can lack experience in the nuances of autistic people’s mental health and confidence in identifying when someone’s autistic traits are or are not a significant factor.⁵,¹²,¹³ There is a developing body of evidence around adapting typical therapies such as CBT but significantly more work is needed.¹²,¹⁴,¹⁵,¹⁶,¹⁷

- **Mental health problems are often misdiagnosed amongst autistic adults.** Autistic people are more likely to be given a sequence of diagnoses for their mental health problems and to disagree with the diagnosis they receive.¹,²,⁵,¹³ The lack of validated assessment tools, high rates of overlapping and co-occurring conditions, and potential for miscommunication between clinicians and autistic people can all make diagnosing mental health problems more difficult.¹³

What we need to find out

"I have anxiety and depression, but it’s taken several visits to the GP to discover this” ¹

The **number one research priority** for autistic people, families and researchers is finding and adapting interventions to improve mental health.²² Currently, too much research on mental health interventions excludes autistic people because of their diagnosis. This exacerbates the knowledge gap on what works for autistic people. Key research areas include:

- What are the environmental and biological causes of mental health problems in autistic people? How do causes such as trauma vary for autistic people compared to non-autistic people?

- Do presentations of common mental health conditions in autistic people vary from their presentations in non-autistic people? If so, do GPs and other health professionals identify those different presentations and adjust their assessment and treatment appropriately?

- What makes a peer support programme personalised and effective for managing or improving mental health in autistic people?²³

- How can talking therapies be adapted to meet the needs of autistic people?
How can different forms of low-level support minimise the risk of mental health problems and the need for more intensive support?

How can health professionals distinguish between physical and mental health difficulties underlying distress in autistic adults who speak few or no words?

Are medications effective in treating mental health conditions in autistic adults? Are autistic people at risk of a different profile of side-effects? Can we determine how different medications are likely to affect different autistic people in order to better target medication?

How can different forms of low-level support minimise the risk of mental health problems and the need for more intensive support?

The Department of Health and Social Care should ensure that supporting autistic people with mental health problems remains a “priority challenge for action” as part of the future strategy.

NHS England is developing a new “framework for adult community mental health services that will encompass the needs of people with a range of diagnoses.” The Minister for Care has indicated that this framework will include mental health support for autistic adults.

NHS England should ensure that the development of this framework is based on the latest evidence, that mechanisms for data collection and evaluation are in place, and that autistic people and their families are involved to ensure that the framework reflects their needs and experiences.

There is a lack of clarity around support for autistic people with mental health difficulties, with mental health services often incorrectly assuming that other, more specialist services exist for autistic people. The continuing integration of commissioning bodies provides an opportunity to close these gaps.

Integrated Care Systems (ICSSs) and Sustainability and Transformation Partnerships (STPs) should be able to demonstrate how their plans include the treatment of mental health conditions in autistic people and ensure the responsible services are sufficiently funded.

Supporting autistic people with mental health problems can be complicated, particularly when they occur with other mental, physical or neurodevelopmental conditions. We do too little to nurture that specialist expertise in the NHS.

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“Was asked to take part in a group, found the group too big, was told I chose not to take part and was left on my own to struggle by myself”

We know a lot more about mental health and autism now than we did when the Autism Act (2009) or Think Autism Strategy (2014) were published but mental health remains a top concern across the autistic community. The Department of Health and Social Care should ensure that supporting autistic people with mental health problems remains a “priority challenge for action” as part of the future strategy.

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Supporting autistic people with mental health problems can be complicated, particularly when they occur with other mental, physical or neurodevelopmental conditions. We do too little to nurture that specialist expertise in the NHS.

Health Education England, NHS England and the Royal Colleges should ensure that there are sufficient health professionals in each area with the specialist knowledge required to meet the needs of their local communities.
"As a cancer patient, some hospital staff were dismissive about how individual pain perception can be. I was told off for 'having a ridiculously low pain threshold'. It felt very judgemental and humiliating at a time when my defences were low."  

Autistic people face substantial health inequalities, are more likely to have poorer general health than non-autistic people and are at increased risk of virtually every cause of death that has so far been studied.

Autistic people are less likely to be satisfied with the healthcare they receive, and to understand and be understood by health professionals. Differences in experience, expression and interpretation can mean that issues like pain are dismissed. International evidence suggests that autistic people are more likely to end up in hospital care or using emergency services.

All healthcare services should be accessible. Autistic people’s health is not the preserve of specialist units. Autistic people are more likely to develop various health conditions including cardiovascular problems, gastro-intestinal disorders and strokes, and are therefore likely to need support from a wide range of healthcare services at some point in their lives.

Adjustments should be tailored to each person. No single set of adjustments works for all autistic people. Autistic people’s communication and sensory needs vary greatly, requiring very different adaptations. For planned appointments, services should try to identify a person’s needs before the visit; various tools for communicating these needs are already being researched and developed. If prior identification of adjustments isn’t possible, services should try to be flexible.

Where possible, services should provide information in advance about what will happen during or before a medical appointment. Uncertainty is a known cause for anxiety amongst autistic people and can exacerbate sensory difficulties. Providing information and pictures in advance can help autistic people prepare for challenging physical environments and social interactions. It can also help autistic people and NHS staff to identify potential adjustments.

There should be more than one way to access NHS services. Giving patients a choice about how they make an appointment (e.g. online instead of over the phone) and when that appointment could be (e.g. at a quieter time of day or during a specific time in a routine) enables them to pick options that work for them.

"I want to be able to tell you but you will not let me write and I do not have the verbal words I need."
What we need to find out

Although there is growing appreciation of the need to make adjustments for autistic people, it is too often assumed that the same adjustments will help the entire autistic population. In reality, autistic people have varied and sometimes conflicting needs. Science can help services to adapt to the diversity of autistic people’s needs and provide more tailored, individualised support. Research specifically needs to address:

▪ What does an autism-friendly health service look like, considering the varying needs of different autistic people?25,26

▪ Are existing measures of pain and function valid in autistic people?25,26

▪ What strategies for self-advocacy and self-management of healthcare are effective in helping groups of autistic people stay well and access services when they need them?25,26

▪ Does a UK-adapted version of the AASPIRE Healthcare Toolkit improve the health and wellbeing of autistic adults?19,20,25,26 How effective are other existing initiatives for communicating needs to health professionals, such as hospital passports?27

▪ What is the impact of implementing adjustments for autistic people on the clinical outcomes (e.g. missed appointments, late presentation, emergency admission, misdiagnosis) and cost-effectiveness of healthcare services?

▪ How do gender identity, sexual orientation, race, class, trauma, or other social factors affect the provision of healthcare services for individual autistic people?

What we should do now

▪ The current Autism Strategy, Think Autism,28 highlights the need for services to make reasonable adjustments as a “priority challenge for action”.29

The next Autism Strategy30 should focus on ensuring that public services can identify an autistic person’s individual needs, tailor adjustments appropriately1,13 and respond to feedback through initiatives such as Ask, Listen, Do.10

▪ Health professionals cannot identify autistic people and the adjustments they need from sight. Few adjustments can be made universally; instead, we need to ensure health professionals have appropriate access to information about people’s needs. 95% of autistic respondents to the Westminster Commission on Autism said they wanted health professionals to have a note on their screen to tell them their patient is autistic.7

The NHS Long Term Plan commits to rolling out “reasonable adjustment flags” for autistic people by 2023/24.31,32 NHS England, NHS Digital and NHSX should ensure digital initiatives provide health professionals with the targeted, timely and appropriate information they need to make adjustments for autistic people.

▪ The Long Term Plan also commits to offering all patients the option of digital GP appointments.32 Further choice around how to reach healthcare services, such as alternative ways of booking appointments and double-time appointment slots, could make it easier for many autistic people to access the care they need.

The NHS should consider implementing additional options for booking appointments across its services.

▪ GPs and other healthcare professionals often lack confidence in their understanding of autistic people’s needs,9,10 and autistic people often have to explain their own needs to professionals repeatedly.1 Currently there are no dedicated specialisms to encourage and nurture expertise in autistic people’s health across the NHS.

The Royal Colleges and Health Education England should recognise the expertise of health professionals who develop specialist knowledge of neurodivergent people’s health, for example by creating a GP with Extended Role (GPwER) accreditation and a corresponding specialist nurse role.

▪ Autistica and the Alan Turing Institute are working in partnership to create a citizen science initiative exploring how autistic people navigate environments, such as healthcare services, which they may find difficult.33

Primary Care Networks, Sustainability and Transformation Partnerships and Integrated Care Systems can help the project develop by providing funding and inviting local autistic people to take part. When data becomes available, PCNs, STPs and ICSs can apply to ask their own research questions and gain insight into improving accessibility for autistic people in their area.
Autistica Action Briefing: Health Checks


Autistica is the UK’s autism research charity. This Action Briefing summarises ongoing work to develop a regular health check for autistic people, as already exists for people with learning disabilities. It was developed in collaboration with the project’s leading researchers as well as autistic people with relevant experience to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, services, regulators and research funders to act on this information. Enabling access to healthcare is a significant step in improving the lives of autistic people and reducing premature mortality. Commissioners, providers and policymakers now need to consider how to most effectively implement evidence-based health checks.

“What we know”

“Autistic people die on average 16 years earlier than the general population.” 1

International evidence suggests that autistic people are more likely to end up using emergency services and requiring hospital care than the general population. 8,9,10

Some autistic people are less likely to interpret signs of ill-health and many face barriers to accessing NHS services. Alexithymia (difficulty identifying your own emotions), different responses to pain, sensory differences, anxiety-inducing uncertainty and mutual miscommunication are some of the issues that can avert autistic people from seeking healthcare when needed. 1,11,12,13,14,15,16

Diagnosing health problems amongst autistic people is not always straightforward. Autistic people are more likely to have a range of co-occurring conditions, 5 and communication differences can mean health problems are unnoticed, misunderstood or not investigated further. 11,17

Health checks can help proactively focus support towards groups facing health inequalities. Regular health checks are already offered to people with learning disabilities and other at-risk groups. 18,19 Implementing health checks for autistic people could provide GP practices with time and resource to provide a systematic and personalised approach to their autistic patients’ needs, give autistic people a more certain route for accessing services, and build knowledge around autistic people which could improve accessibility and health outcomes more generally. It is possible that health checks will become highly cost-effective care for autistic people by reducing the need to access tertiary services.

“What we need to find out”

“Everything needs to happen quicker, there appears to be a reactive response to mental health needs rather than proactive approaches.” 1

Autistica are funding research at Newcastle University to design and test a health check for autistic adults. The study is among the first ever to be completely co-designed with autistic people and will investigate a range of issues, including the barriers autistic people face in accessing primary care and the development of a pre-appointment digital tool to help deliver the health check. The research will be conducted as part of clinical practice, and consider the costs and value involved. Other research projects that could help to ensure health checks are implemented as effectively as possible include:

How should health checks for autistic people be implemented? What is the impact of health checks on clinical outcomes (e.g. missed appointments, emergency admissions or misdiagnosis) and the cost-effectiveness of service delivery?

Using existing secondary data, what are the rates of emergency admissions amongst autistic people in the NHS? What are the most common causes of hospitalisations, A&E attendance or visits to urgent treatment centres for autistic people?
How can the health check currently in development be adapted for autistic children and young people?

What public health campaigns are effective in driving uptake of health checks, including in harder-to-reach communities?

Can elements of this health check be adapted to add value to the existing learning disability health check for autistic people with learning disabilities?

How can services most effectively identify service users who could benefit from health checks, including those who may be undiagnosed?

How can personalised support be delivered to autistic people after a health check, particularly with respect to common conditions?

Can health checks be used to monitor wellbeing? How can measures of pain and wellbeing be used or adapted for autistic people through the annual health check?

The NHS Long Term Plan committed to “pilot the introduction of a specific health check for people with autism, and if successful, extend it more widely”. Autistica and the National Autistic Society have recruited a Policy Officer to tackle the practical and policy challenges in delivering health checks.

Despite NICE recommendations, the digital infrastructure has not been prepared to enable GPs to invite local autistic people to health checks. The NHS Long Term Plan commits to ensuring that “clinicians can access and interact with patient records and care plans wherever they are.”

Autistic people’s diagnoses are so inconsistently coded across GP records that it would be difficult for practices to identify those in their area who should be invited for health checks.

Implementing these health checks effectively in clinical settings will require time and resources from already overstretched health professionals, many of whom do not feel confident supporting autistic people.

The CQC currently checks whether health checks for people with learning disabilities are delivered when it inspects GP practices.

HEE and the Royal Colleges should consider ways to recognise members who develop expertise in the nuances of neurodiverse people’s health, including accrediting a General Practitioner with Extended Role (GPwER).

The CQC inspections should also look at whether practices are prepared to deliver health checks for their local autistic community.

What we should do now

“Unless my appointment is specifically about autism it doesn’t seem to be on my file... Often they obviously don’t believe me.”

The NHS England should work with Autistica and National Autistic Society policy teams to deliver this commitment using an evidence-based approach with the involvement of the autism community.

NHS England and GP system providers need to ensure GPs can access information they need to invite autistic people for health checks, with relevant information possibly becoming part of the health record and accessible to individuals.

NHS Digital and NHS England should work closely with the Royal Colleges and autism community to produce a simplified list of codes and then support Integrated Care Systems and Sustainability and Transformation Partnerships to audit the quality of local records.

NHS England should work with the Royal Colleges, Health Education England and others to agree how clinicians can be supported and incentivised to offer regular health checks for autistic people.

Every Primary Care Network area should have health professionals with expertise in the nuances of autistic people’s health to support other local areas in adjusting the care they provide. Currently we do not do enough to nurture that specialist expertise in the NHS.
Autistica Action Briefing: Epilepsies


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about epilepsies in the autistic community. It was developed in collaboration with leading researchers and autistic people and families with lived experience of the topic to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, NICE and public research funders to act on this information. The evidence gaps around autism and epilepsy are putting lives at risk. Through research and policy, we must begin empowering the NHS with better evidenced, personalised diagnostic, monitoring and treatment options.

"So many of the unexpected and preventable deaths in the news are of people with autism and epilepsy. No-one ever said our son was more likely to die."

What we know

- Epilepsy is the leading cause of early death for autistic people with a learning disability. On average, half of the people in that group do not live to see their 40th birthday.2,3
- Between 15% and 40% of people with epilepsies are autistic, compared to just 1% of the general population.4,5,6,7,8 Epilepsies are particularly prevalent amongst autistic people with a learning disability.3,10
- Autistic people appear to be more likely to have epilepsies which resist treatment.9,11 Autistic people with epilepsies face a higher risk of early death than autistic people without epilepsies and non-autistic people with epilepsies.12
- Autistica is funding the first and currently only study in the world on the use and efficacy of anti-seizure medications in autistic people. Over 1,400 clinical trials have looked at the effectiveness of major anti-epilepsy medications, but we could not find a single well-controlled trial that tested their use in autistic people.13
- Epilepsies can also present differently in autistic people. For example, for a substantial proportion of autistic people with epilepsy, this develops in adolescence, whereas in the general population seizures more commonly begin in early childhood.4,6

What we need to find out

- I have epilepsy but am very sensitive to medication. It is sometimes a toss-up between staying seizure-free and being able to function at all due to side effects."1

Epilepsies are one of the biggest killers of autistic people, particularly those with learning disabilities,2,3,12 and existing treatments are often ineffective.2,12,13 This is too often accepted as inevitable, but research has the power to prevent tragic premature deaths of autistic people with epilepsies. Developing personalised treatments to prevent epileptic seizures should be one of the highest priorities of autism science but almost no research is working towards it.14 Autistic people, families and researchers at our Autism and Epilepsy Global Summit in 201715 identified the following questions as key priorities for research:

- Which autistic people develop epilepsy, when and why?
- Does medication, including anti-psychotics, prescribed at critical developmental stages lead to onset of epilepsy?
- What are the rates of emergency medication use for epilepsy in autistic people?
- Which side effects are more or less common/problematic in autistic people with epilepsy?
- What are the rates of SUDEP (Sudden Unexpected Death in Epilepsy) in autistic people? What are the key risk factors for premature death (including SUDEP) in autism and epilepsy? How can we better educate autistic people, families and caregivers about these risks?
- How do we develop effective care plans for autistic people with epilepsy and ensure they are adhered to?
What are the factors leading to build-up of anxiety in autistic people with epilepsy and how can these inform management?

Does sleep differ in autistic people with and without co-occurring epilepsy?

What, if any, are the genes that drive autism, epilepsy and the co-occurrence of both?

To what extent are seizures a factor in the increased use of emergency healthcare services by autistic people?

Autistic people with learning disabilities continue to be significantly under-represented in impactful health research. Without a concerted effort to improve the infrastructure for high quality science, we will continue to watch the tragic progression of deaths in NHS care.

At present, there is a significant evidence gap for treating epilepsies in autistic people. Autistica is committed to working on this area but tackling premature deaths from epilepsy in autistic people will require a sustained and coordinated programme of research.

To drive progress, NIHR and UKRI should collaborate with third sector funders to establish a virtual research network on autism and epilepsy and ensure impactful research is being supported across all those organisations’ funding streams.

The impact of epilepsies in the autistic community was barely known when the Autism Act (2009) and Think Autism Strategy (2014) were published. The Government recently made reducing early death the primary aim of the Autism Strategy and have launched a review of the Strategy for the future.

The Department of Health and Social Care should ensure that preventing death from epileptic seizures becomes a “priority challenge for action”, as part of a wider theme on reducing morbidity and early death.

The current NICE guidelines on epilepsies do not mention autism, even though up to 4 in 10 people with epilepsies are autistic and there is evidence indicating clinical differences in how their conditions present.

NICE are currently reviewing their epilepsies guidelines for children and adults. They should take this opportunity to ensure those guidelines alert health professionals to the different clinical requirements that an autistic person with epilepsy may have.
Autistica Action Briefing:  
Other Co-Occurring Conditions

April 2019

Autistica is the UK’s autism research charity. A number of our Action Briefings have focused on specific health problems that autistic people often face. This briefing summarises the most important scientific findings about other co-occurring conditions. It was developed in collaboration with leading researchers and autistic people and families with lived experience of the topic to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and research funders to act on this information. There is increasing evidence that autistic people are more likely to experience a range of physical and neurological health problems; the services and policies focused on tackling those conditions need to consider ways to address these health inequalities.

"I struggle with debilitating fatigue and pain that no doctor has been able to explain. Some doctors say it’s because I’m autistic. No support has been offered. Because of this, I’m unable to work or leave my house for extended periods of time."  

What we know

- Autistic people generally experience poorer health outcomes than the general population and are more likely to develop a wide range of conditions including heart disease, diabetes, stroke, Parkinson’s disease, allergies, gastro-intestinal disorders and autoimmune conditions.

- Difficulties with sleep are common amongst autistic people, who often experience a longer delay before falling asleep and poorer refreshment on waking up. Sleep disorders are associated with a variety of other health problems.

- Autistic people appear to face increased rates of obesity and diabetes. Reasons for this include difficulties eating a varied diet from issues such as sensory differences, and barriers to accessing physical activity.

- While autism is not a mental health condition, mental health conditions are the norm rather than the exception for autistic people, and suicidality and suicide rates are exceptionally high within the autistic community. Autistica have recently published a series of research and policy recommendations to improve mental health in autistic people.

- Many autistic people are prescribed psychotropic medication, such as antipsychotics, for long periods, even if they haven’t been diagnosed with the conditions those drugs are intended to treat. Giving someone a treatment they don’t need is dangerous, and the long-term use of psychotropics is associated with a range of health problems.

What we need to find out

- Are autistic people at greater risk of cardiovascular events, gut problems, stroke, diabetes, neurological and autoimmune conditions than non-autistic people? Why is this, and how can these risks be reduced?

- What can we learn about the current use of residential facilities by older autistic adults?

- What is the incidence of Parkinson’s disease among autistic people and what are the associated risk factors?

- How can researchers and autistic people work in partnership to investigate biological factors affecting the health and wellbeing of autistic people?

- Are hypermobility syndromes more frequent in autistic people and why?

- What are the factors affecting problems with sleep in autistic people? How can we improve sleep in autistic people?

- How effective are existing public health initiatives, such as social prescribing and encouraging healthy diet and exercise, in reaching autistic people? How can these initiatives be improved for autistic people?
A number of health conditions had only begun to be linked to autistic people when the Autism Act (2009) or Think Autism Strategy (2014) were published. The Government recently made reducing early death the primary aim of the Autism Strategy and has launched a review of the Strategy for the future.

We now know that autistic people are more likely to experience poor outcomes from a range of health conditions. The Department of Health and Social Care should ensure that managing co-occurring conditions becomes a “priority challenge for action”, as part of a wider theme on reducing early death.

The NHS Long Term Plan includes detailed commitments about tackling cancer, cardiovascular disease, strokes, diabetes and respiratory disease.

All clinical priority teams within NHS England should consider the health inequalities facing autistic people and people with learning disabilities in their ongoing work.

The Long Term Plan committed to piloting specific health checks for autistic people and, if successful, to extending these more widely. Autistica and the National Autistic Society have recruited a Policy Officer to tackle the practical and policy changes in delivering health checks.

NHS England should work closely with Autistica and National Autistic Society policy teams to deliver this commitment using an evidence-based approach with the involvement of autistic people and their families.

The NHS also recently announced that the STOMP-STAMP programme to stop the overmedication of autistic people and people with learning disabilities would be expanded. Anonymised NHS data is vital for ensuring that programmes like STOMP-STAMP can be delivered and monitored effectively. Public Health England recently found that there wasn’t enough data available to analyse how many autistic adults are at risk of overmedication.

NHS England, NHS Digital and local health services need to prioritise improving the consistency and quality of NHS records concerning autistic people’s healthcare, particularly within primary care.

The NHS Long Term Plan highlights “research-active hospitals have lower mortality rates” and prioritises action to reduce preventable deaths amongst autistic people. Few clinical innovations in different specialisms are focusing on testing the effectiveness of interventions for autistic people despite the high rates of health inequalities.

The National Institute for Health Research, NHS England, and public, private and third sector research funders need to collaborate and support more healthcare professionals to become involved in impactful autism research.
Autistica Action Briefing:
Access to Adult Diagnosis


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about access to adult diagnosis. It was developed in collaboration with leading researchers and autistic people with experience of diagnosis in adulthood as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. Hundreds of thousands of autistic adults in the UK do not have a recorded diagnosis. This can cause serious challenges for those people and for the NHS. Public policy needs to ensure autistic adults can access recognition and support when they need it.

“I was able to make so many improvements to my life after I understood I was autistic. I could have made them earlier and saved so much pain, time and money. Most of my mental health problems have been resolved now I have a better understanding of myself as an autistic person and had therapy which understood this.”

What we know

“I was unable to work, barely eating, and had recently cut myself again. Doctors told me I couldn’t be autistic because I could speak and was ‘high functioning’. I did not fit the image in their heads.”

- Most autistic people are adults, but most autistic adults are not diagnosed. Receiving a diagnosis of autism can provide long-awaited answers and insight into a person’s strengths and difficulties, enabling them and others to make adjustments to improve their well-being.

- Relatively few autistic adults are diagnosed, especially those in older age, because they largely grew up in a time when autism was rarely recognised. However, adults seeking an autism diagnosis today continue to face a wide range of barriers to assessment, including difficulties getting a referral to diagnosis services, inconsistent pathways, lengthy waiting times and a lack of information during the process.

- Between two thirds and three quarters of adults wait longer than the recommended 12 weeks in NICE guidelines for an assessment, with one third waiting longer than 18 months. Another study found that autistic adults wait an average of two years after first seeking professional help to receive an autism diagnosis. Although there is some evidence to suggest that adjustments to the referral and diagnosis process can reduce waiting times, efficiency savings alone will not enable diagnostic services to cope with rising demand.

- Not every part of the country has a pathway for diagnosing autistic adults. NHS.uk recognises that “not all areas have a specialist autism assessment centre” for adults and referral routes in over 4 in 10 local authorities are unclear or out of area, with some authorities having no pathway for diagnosing adults at all.

- People with co-occurring mental health conditions find it even harder to access diagnostic assessments for autism, waiting longer on average to receive a diagnosis. This is a particular problem because almost 8 in 10 autistic adults will experience mental health problems, which are a leading reason for someone to seek an autism assessment.

What we need to find out

“I have a long history of mental health issues (including inpatient psychiatric care for an eating disorder). Not one professional suggested that I could be autistic.”

Adult diagnosis is a top research priority for the autism community, yet historically very little autism research has focused on adults, with older adults being particularly excluded from research. We know that autism diagnosis can bring a sense of relief and understanding and that many autistic adults have a positive experience of the diagnosis process. To ensure that this is accessible to all autistic adults, we need to find out:

- Which service models for diagnosing autism in adults are most effective and sustainable? How does the variation in service models nationwide affect access to diagnosis?

- How can we improve the identification of autistic adults within mental health services and the criminal justice system?
Do health professionals in primary and secondary care have the confidence and knowledge to identify potential autistic traits and make appropriate referrals?

What are the most effective ways to support adults waiting for a diagnostic assessment, including mental health support? What is the most appropriate way to manage self-referrals?

How can diagnostic teams sustainably support professionals in their local health, education, welfare or criminal justice systems to recognise when someone might be autistic and could benefit from a diagnostic assessment?

How can we develop public health initiatives around autism diagnosis to reach under-represented groups?

**What we should do now**

"Waiting times for diagnosis are extremely lengthy. Almost makes you give up at the start. It is not clearly signposted, so difficult to even start the process." 1

- Every English Autism Strategy has committed to improving diagnosis for autistic adults.28,29 In reality, funding and support for the specialist services needed to deliver adult diagnosis has fallen far short of these ambitions and of increasing demand.

- The next Autism Strategy should explicitly commit to increasing the availability of specialist autism diagnostic services for adults.30 The Department of Health and Social Care and NHS England should work closely to ensure that Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) recognise that commissioning effective adult diagnosis pathways is essential for tackling health inequalities and reducing inappropriate service use.

- The NHS Long Term Plan did not mention the challenges adults face in seeking an autism diagnosis,31 despite including autism amongst its key clinical priorities.32 Most autistic people are adults but most autistic adults are undiagnosed; increasing the number of diagnosed adults would be a significant step in tackling health inequalities.33 The NHS Long Term Plan workstream on autism should prioritise action to identify optimal pathways for diagnosing autism in adulthood and address geographical disparities in access.

- Changes to the Mental Health Services Data Set (MHSDS) last April means that more reliable data is becoming available about autistic adults’ interactions with NHS services.34,35 This could help provide valuable insight into making diagnosis pathways more effective and efficient.

- NHS Digital, NHS England and National Institute for Health Research should meet with the Department of Health’s autism data group to discuss commissioning an analysis using the MHSDS and other public datasets into the patterns of service use amongst adults who later receive an autism diagnosis.

- Rising demand can mean that people who seek an autism assessment are left on waiting lists for years without support or an estimate of when they will be seen.15

- STPs and ICSs should know whether local diagnostic services are resourced to provide adults on waiting lists with regular updates regarding their position and any support available.
Autistica Action Briefing:
Adult Diagnosis Process


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about the adult diagnostic process. It was developed in collaboration with leading researchers and autistic people with experience of adult diagnosis as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. There is growing evidence around how to effectively diagnose autistic adults, but to make further progress, the unwarranted national variation between diagnostic pathways must be tackled.

"The doctor dropped the bombshell that I ‘clearly have autistic traits’ but she could not give me a diagnosis because they needed ‘parental input’. She knew my parents were dead but had dragged me through a second appointment – I am 60 years old."

What we know

"My diagnosis has been one of the best things ever to have happened in my life – liberating in so many ways and I am truly grateful."

- The process and service configuration for diagnosing autistic adults varies widely across the country. Where services are available, they collect different information ahead of assessment, use different diagnostic tools, involve different groups of health professionals, and ultimately diagnose very different numbers of autistic adults.2,3,4

- Evidence for the effectiveness of existing diagnostic tools and screening measures in adults has been limited in the past,5,6 but an evidence base is beginning to emerge.7,8 Some autistic adults report being assessed with tools designed for children which they found inappropriate.1 Services should be flexible about who acts as an informant in the assessment of adults; insistence on parent-informants can lock out those whose parents are estranged or deceased.1,9

- Existing diagnostic tools can be ineffective in distinguishing autism from mental health conditions, sometimes resulting in misdiagnosis.6,9,10 This is particularly problematic for the 8 in 10 autistic adults who experience co-occurring mental health problems,11 as mental health difficulties are a leading reason for adults to seek an autism assessment.3,12,13

- There is growing consensus between clinicians and autistic adults around aspects of the diagnostic process that should change, such as the need for expertise in mental health conditions and more effective standardised diagnostic tools.3 This creates an opportunity to build on best practice and develop more consistent pathways. Autistica are funding a programme of research at Newcastle University to improve adult diagnosis;14 two recent workshops stimulated discussion amongst autistic people, clinicians and policymakers and led to a list of consensus statements that could be implemented now.3

What we need to find out

Adult diagnosis is one of the top research priorities of the autism community,15 yet up until now little autism research has focused on it.16,17,18 We know that in some areas, adults are having a positive experience of the diagnostic process.3 To ensure that this becomes the norm, we need to find out:

- How do rates of autism diagnosis in adults vary nationwide? Which autism diagnostic tools and screening processes are currently used in areas with different rates of diagnosis?

- Which diagnostic models are considered best practice with respect to cost-effectiveness and accuracy? Is there sufficient capacity to manage NHS referrals in all areas of the country?

- How do rates of diagnosis vary across different combinations of professionals used to diagnose autism in adults across the UK? Is there an optimal group of professionals for adult autism diagnosis?

"Diagnosis has been life-changing. I know where I fit, and why I don’t fit where I don’t. I’ve developed strong positive views about neurodiversity. It would be good if medics could understand how adult diagnosis can be so valuable."

24
What are the risks of further harm and distress being caused for adults throughout the autism diagnosis process? What are the benefits of the diagnostic process as an autistic adult? How can we ensure that the diagnostic process is a positive and constructive experience relevant to the current needs of the person?

What diagnostic tools, or what adaptations to diagnostic tools, are effective in identifying autism in the presence of co-occurring mental health conditions? How can clinicians effectively screen for mental health conditions in the diagnostic pathway for autism?

What is the clinical and cost-effectiveness of the various new adult diagnosis tools currently in development?

While child diagnosis pathways are often poorly implemented in practice, for adults these pathways are often seriously underdeveloped, underfunded or non-existent. However, adult diagnosis is not mentioned in the NHS Long Term Plan despite autism being included as a clinical priority.

To reduce health inequalities, the NHS Long Term Plan workstream on autism should prioritise action to tackle unwarranted variation in processes and outcomes between diagnostic pathways.

It is often unclear which services are commissioned to diagnose autistic adults with a learning disability, autistic adults without a learning disability and autistic adults (of either group) within local mental health services. Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) should be able to demonstrate to NHS England that their commissioning arrangements explicitly resource appropriate services for each of these separate groups. Those arrangements should specify the responsibility of local Community Learning Disability Teams in diagnosing each group.

Most adult autism diagnostic teams work in relative isolation. Establishing networks to help teams share information and compare approaches to complex cases (vignettes) could help reduce some variations in diagnostic approaches.

NHS England should work with the Royal College of Psychiatrists and other professional bodies to map and supplement existing networks on adult autism diagnosis across each region and relevant specialism. This must accompany, not replace, action at a national level to improve adult autism diagnosis.

Changes to the Mental Health Services Data Set (MHSDS) last April means that more reliable statistics on autism diagnosis in NHS services can begin to be published from 2019. As it becomes more complete this dataset could help identify unwarranted variation in diagnostic rates and waiting times across the NHS.

NHS Digital should publish an annual analysis of the rates of autism diagnosis amongst adults, the rates of referral for autism diagnosis and the referral-to-assessment times recorded in the MHSDS. Where appropriate, figures should be published by age, gender, ethnicity, geographical location and commissioning area (including STP and ICS boundaries).
Autistica Action Briefing: Post-Diagnostic Support for Adults


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about post-diagnostic support for autistic adults. It was developed in collaboration with leading researchers and autistic people with experience of adult diagnosis as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. Chances are being missed to tackle autistic health inequalities. Supporting autistic adults when they receive a diagnosis and throughout their lives is crucial for improving those outcomes. Services and public policy need to see post-diagnostic support as their opportunity to make a difference.

“What we know

- A lack of support after diagnosis is the norm rather than the exception, particularly for autistic adults without a learning disability. Despite large demand for post-diagnostic support and a significant impact on outcomes, the options available for autistic adults are often limited or non-existent.

- Services are often not commissioned or funded to support people after diagnosis. Despite growing clinical consensus that follow-up support should be offered to maintain good health and optimise quality of life, many diagnostic teams are not resourced to implement this. Some can only offer group-based services which are inaccessible to some autistic people, whilst others cannot offer any support at all.

- While autism is not a mental health condition, mental health conditions affect the majority of autistic people. There is an opportunity to introduce low-level support which could reduce the need for crisis or inpatient services.

- Autistic people have poorer health outcomes and are more likely to experience a range of conditions. Following up effectively after diagnosis creates opportunities to identify and overcome health inequalities, a key priority in the NHS Long Term Plan.

- Autistic people report a lower quality of life and face exceptionally high rates of unemployment and social isolation, both of which also impact health outcomes. Support beyond diagnosis could enable autistic people to access opportunities to play a more active role in their communities and the economy.

“What we need to find out

Too little research has focused on the ideal ways to support autistic people as adults. Receiving an autism diagnosis is a key opportunity to help autistic adults access the support they need. For this to be effective, research needs to consider:

- Which services and professionals are currently involved in supporting autistic adults immediately after diagnosis in the UK? How effective are existing post-diagnostic support models in improving quality of life for autistic adults?

- What methods of delivering psycho-educational support are effective at helping autistic adults come to terms with what their diagnosis means and maximising their quality of life?

- How can diagnostic teams most effectively coordinate support for autistic adults after diagnosis between referrals to mainstream services or specialist post-diagnostic services?

- To what extent is longer-term, low-level support effective in improving outcomes for autistic adults? How can effective “step-on, step-off” support, available as and when needed by autistic adults, be made sustainable?

- Are peer support programmes effective for improving post-diagnostic outcomes (e.g. mental and physical health, wellbeing, understanding of autism and autonomy) for autistic people? How can we optimise peer support programmes for personalised goals?
Autistic people require varying levels of support at different points in their lives, for example during transition to adulthood, commencing employment, retirement and bereavement. However, there are currently few contact points within the NHS for autistic adults after diagnosis, aside from inpatient settings and services for people with learning disabilities.

NHS England should consider supporting Sustainability and Transformation Partnerships and Integrated Care Systems to pilot models of ongoing low-level support for autistic adults and collect data to evaluate the effectiveness and sustainability of different approaches.

Post-diagnostic support has a vital role to play in tackling poor health outcomes among autistic adults, and there is increasing evidence about how to do it more effectively. The Long Term Plan made tackling autistic health inequalities an NHS clinical priority but how diagnosis and ongoing support for adults will be improved has not yet been specified. The NHS Long Term Plan workstream on autism should prioritise work to identify optimal diagnostic and post-diagnostic pathways for autistic adults. This should be considered alongside other initiatives in the Long Term Plan, like the introduction of health checks for autistic people.

The 2014 Adult Autism Strategy set out that making “person-centred local health, care and support services” available for autistic people was one of the “priority challenges for action”. This is still not the case in most areas. The importance of person-centred care was recently highlighted by the National Autistic Taskforce.

The Department of Health and Social Care should ensure that its new Strategy includes a specific focus on supporting autistic adults after diagnosis.

Autistic people frequently report the need for low-level preventative support, and such approaches have found success in other fields such as mental health. The Department of Health and Social Care, NHS England, and public, private and third sector research funders need to collaborate to facilitate research around low-level, cost-effective interventions to support autistic people and their families beyond diagnosis.

What we should do now

“Feeling shaken and vulnerable, I went to my GP to see what help or support might be available in adapting to life with my diagnosis, and the answer was ‘None’."

Changes to the Mental Health Services Data Set last April mean that more reliable data will become available about autistic adults and their interactions with NHS services. This data could help provide valuable insights into the healthcare services autistic adults use beyond diagnosis.

NHS Digital, NHS England and the National Institute for Health Research should meet with the Department of Health’s autism data group to commission an analysis of the services autistic adults use after they have been diagnosed, using the MHSDS and other public sector datasets.

NHS England should consider supporting Sustainability and Transformation Partnerships and Integrated Care Systems to pilot models of ongoing low-level support for autistic adults and collect data to evaluate the effectiveness and sustainability of different approaches.
Historically, autism research disproportionately focused on men and boys.\(^{31}\) We now know that many autistic women and girls went undiagnosed in the past and continue to be missed today.\(^{7,8}\) To ensure better recognition of autistic women and girls in future, research now needs to consider:

▪ Are existing diagnostic tools as sensitive to autistic traits in women compared to autistic men?

What we know

▪ **Thousands of autistic women and girls in the UK may be undiagnosed and overlooked.** Autism appears to be more common in males than females\(^{2}\) with a recent meta-analysis estimating that the ratio is about 3:1.\(^{3}\) Recent biological research has pointed towards reasons why this might be the case.\(^{4}\) However, estimates of this gender gap have closed significantly over time.\(^{4}\) Smaller differences in the number of men and women have been found in autistic adults,\(^{5}\) suggesting that autistic women are more likely to grow up undiagnosed.\(^{3}\) The gender gap also appears narrower amongst autistic people with learning disabilities,\(^{6}\) which suggests more women without a learning disability are being missed.

▪ **Women and girls tend to be diagnosed later\(^{7,8}\) and are less likely to receive a diagnosis than men and boys with similar levels of autistic traits.**\(^{4,9}\) Research suggests autistic girls ‘fly under the radar’ unless they have additional difficulties.\(^{10}\) Some studies have found gender-based differences in scores on commonly used autism diagnostic measures.\(^{11,12,13}\) This may be due to bias in the design and/or application of these tools.\(^{4,14}\)

▪ **Stereotypes can prevent autistic women and girls from receiving a diagnosis.** Presentations of autistic traits that are more common in women and girls\(^{11,15}\) may not always be recognised by professionals.\(^{16}\) Autistic women frequently report having their concerns dismissed due to misconceptions that autism is a “male” condition, that the abilities and interests of autistic people are the same between genders and that women and girls are stereotypically “quiet” and “shy”.\(^{1,15,16,17}\)

▪ **Women and girls who ‘camouflage’ autistic traits face further delays in diagnosis.** Research is beginning to understand that many autistic people may consciously or unconsciously mask their differences to seek acceptance, which can impact their mental health.\(^{16,17,18}\) On average, autistic women and girls are more likely than autistic men and boys to camouflage, in part due to gendered cultural expectations.\(^{4,19}\) One study found that while autistic people across all genders report camouflaging, autistic women were much more likely to report being denied a diagnosis on that basis.\(^{18}\)

▪ **Autistic women and girls may be misdiagnosed with mental health conditions.**\(^{16,20,21,22}\) Autism is not a mental health condition, but autistic people often do experience mental health issues and some autistic traits can be mistaken for symptoms of mental ill-health.\(^{20}\) Diagnostic tools can be ineffective at accounting for these distinctions.\(^{21}\)

▪ **Autistic women and girls face serious health inequalities.** Autistic women with a learning disability are among those at highest risk of early death in the autistic community.\(^{24,25}\) Autistic women are also markedly more likely to die by suicide than non-autistic women,\(^{24,25,26}\) and report lower quality of life than their male peers.\(^{27}\) Initial evidence suggests that autistic women are at greater risk of abuse.\(^{28,29,30}\) Investing in diagnosis could help deploy resources more effectively towards supporting those women throughout their lives.

What we need to find out

▪ “I was misdiagnosed with mental health conditions from my early teens to my forties.” \(^{1}\)

Unfortunately, the stereotype is males that speak in a monotone voice and are obsessed with trains or machinery, and this needs to change.” \(^{1}\)
What patterns of prior diagnosis (or misdiagnosis) are common in autistic women? Are those patterns different in men? What other characteristics or experiences are common in women and girls before receiving an autism diagnosis?

What is the role of camouflaging in the delayed or missed diagnosis of autistic women and girls?

Are there significant differences in wellbeing between autistic women diagnosed in childhood and those diagnosed in adulthood?

What are the perceptions of GPs and other health professionals about autism in women and girls? To what extent does unconscious bias affect the time taken for women and girls to access diagnostic assessment?

How can education and health professionals become more proficient at identifying possible signs of autism in girls and young women, and effectively co-ordinate assessment and support? How can clinical teams gain the skills needed to make timely valid diagnoses?

The “priority challenges for action” underpinning the most recent Adult Autism Strategy in 2014 included: “I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.” This should be just as true for women as for men.

The Department of Health and Social Care’s new Strategy should address the specific challenges women and girls face in autism diagnostic pathways.

The Long Term Plan made autism an NHS clinical priority but it did not specify how adult diagnosis would be improved or how gender inequalities around autism would be addressed. Improving adult diagnosis is an important step in tackling health inequalities, particularly for women who tend to be diagnosed later in life than men.

The NHS Long Term Plan workstream on autism should consider ways to remove barriers to diagnosis for autistic women, as part of wider work to tackle unwarranted variation in adult diagnostic pathways.

Women and girls often present in eating disorder or other mental health services before receiving an autism diagnosis.

NHS England should consider auditing identified autistic women and girls in eating disorder and inpatient mental health settings to establish whether there were missed opportunities to intervene earlier, had autism been considered.
Autistica Action Briefing: Employment


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about employment in the autistic community. It was developed in collaboration with leading researchers and autistic people as an insight into the latest evidence.

We strongly urge the Government, public research funders and public, private and third sector employers to act on this information. Employers are missing out on a vast talent pool. Many autistic people want to work but don’t experience a level playing field. There’s been a lot of discussion around employment and autism; we must now build an evidence base about what works in helping talented autistic people to flourish.

“I don’t apply for jobs because I’m scared.”

What we know

- **Unemployment rates are exceptionally high amongst autistic people, even compared to other disability groups.**
  Although most autistic people want to work, and make positive contributions to the workplace when they do, autistic people with and without learning disabilities frequently struggle to find work.

- **Autistic people also face high rates of underemployment.** For those who do find work, it is disproportionately part-time, temporary, casual, or roles for which they are overqualified.

- **Typical recruitment processes may be inaccessible for many autistic people.** Unclear application forms, abstract questions, unsuitable sensory environments and the fact that interviews often operate as a test of social ability can disadvantage autistic people and make it harder for them to demonstrate their suitability for a role.

- **Autistic people in work face a range of barriers to maintaining employment and reaching their potential.** Autistic people can face extra challenges in navigating the sensory environment of an office, handling the social aspects of the workplace, dealing with unstructured working practices, managing anxieties at work and maintaining good mental health more generally. These barriers are compounded further for autistic people with learning disabilities, who may require continuous support in the workplace and have difficulty finding suitable employment opportunities to match their skills as well as transferring learning from one setting to another.

- **It is likely that medium-to-large employers already have autistic people within their workforce.** Autistic people are more likely to have strengths in areas such as attention to detail, focus and information processing which can be useful in various sectors. However, like the rest of the population, autistic people’s skills vary and they may find employment in a wide range of fields. Autistic people’s employment outcomes improve when they are matched with jobs that fit their skills and interests. Most autistic adults are undiagnosed and some do not disclose their diagnosis to their employer for fear of discrimination.

- **There are known links between unemployment, health and wellbeing,** and high unemployment amongst autistic people could further entrench health inequalities. In particular, unemployment is a risk factor for suicide, one of the leading causes of early death for autistic people. Employment can positively affect the quality of life and wellbeing of autistic people as well as improving productivity.

What we need to find out

“Despite feeling extremely stressed, the fear of judgements, stigma and discrimination prevents me from being open about being autistic, however I wish I could be.”

Supporting autistic people to maximise their potential in the workplace is one of the top research priorities for the autism community. Despite this, there is still little research on the best way to attract and retain autistic employees. Autistica and University College London (UCL) have recently launched Discover Autism Research & Employment (DARE), the only national evidence-gathering employment programme for autistic people. Vital things to find out include:
What we should do now

The “priority challenges for action” underpinning the most recent Adult Autism Strategy in 2014 included: “I want support to get a job and support from my employer to help me keep it.” The Government has also committed to get one million disabled people into work, which could include many autistic people who want to work but cannot find employment.

The Government’s next Autism Strategy should commit to finding out what will work in ensuring that unemployed or underemployed autistic adults can succeed in their careers. To achieve this, the Department for Work and Pensions’ Work and Health Programme should partner with autistic people to explore what supports will help them find and secure suitable employment.

Autistica and University College London have launched DARE, an initiative to gather evidence and improve best practice for employing autistic people across all industries. The NHS Long Term Plan included a promising commitment to offer more supported internships and paid employment opportunities to autistic people.

Public sector bodies like NHS England should consider participating in the DARE initiative to ensure they are securing the benefits of a neurodivergent workforce and that they are contributing to the continual learning about the most effective ways to support autistic people in employment.

Autistica and UCL have recently opened a Neurodiversity Employment Survey to understand the employment experience of neurodivergent people and identify evidence gaps. The survey is open to everyone, in order to compare neurodivergent experiences with each other and against the experiences of neurotypical people.

Individuals should consider taking the survey, and public, private and third sector organisations should promote the survey across their networks, to ensure the full range of experiences are represented.

At present, no information is collected regularly on the employment of autistic people.

The Department of Work and Pensions should explicitly include autism in the Labour Force Survey’s questions and statistics on disability.

It is likely that most large employers already have neurodivergent people within their workforce.

Public sector bodies should develop a Neurodiversity Strategy or incorporate neurodiversity into their existing Diversity & Inclusion Strategy.
Autistica Action Briefing: Sensory Needs & The Built Environment


Autistica is the UK’s autism research charity. This briefing summarises the most important scientific findings about environmental adaptations for autistic people. It was developed in collaboration with leading researchers and autistic people with experience of the topic as an insight into the latest evidence.

We strongly urge the Government, public services, commissioners, local authorities and public research funders to act on this information. No single type of environment is completely ‘autism-friendly’. We now must act to account for the diversity of autistic people’s needs to ensure that all autistic people can exercise their right to access public spaces.

What we know

- Over 9 in 10 autistic people process sensory information differently to their non-autistic peers. For example, this could mean finding everyday sounds and textures overwhelming, difficulty recognising pain and where the body is in space, or seeking out lights and needing to move around. Someone can be both hyper- and hypo-reactive to different sensory stimuli as well as experiencing sensory-seeking traits.

- Autistic people’s sensory experiences are diverse and sometimes conflicting. Some autistic people are most comfortable in stimulating environments which other autistic people find overwhelming. Rather than trying to fit one stereotyped idea of ‘autism-friendly’, we should focus on ensuring access to a range of environments to meet different needs as well as providing accurate information to allow autistic people to make informed decisions.

- Difficult sensory environments can prevent autistic people from accessing public spaces and services. This ultimately has a knock-on effect on wider outcomes, entrenching existing inequalities. For example, autistic people regularly struggle to make the most of medical appointments due to difficulties communicating in inaccessible environments.

- Differences in sensory responses can also impact autistic people’s health. Multiple studies have found links between sensory reactivity, uncertainty and anxiety, which affects over half of autistic adults and 4 in 10 autistic children. Sensory reactivity is also associated with distressed behaviour and difficulty sleeping and eating.

What we need to find out

Autistica and the Alan Turing Institute are building a citizen science platform to explore how autistic people navigate different environments. The project should help answer some of the questions that autistic people, families and researchers have highlighted as top research priorities. These include:

- Which particular environments are more or less challenging for different groups of autistic people?

- What are the perceived physiological and behavioural indicators of sensory experience for autistic people? Do these change over time or in different contexts?

- What strategies do autistic people already use to cope with difficult environments? What strategies positively impact sensory wellbeing?

- How can we effectively create environments which people can adjust as they use them to account for their needs?

"When anxiety is really bad, having to go to the GP is like having to climb Everest. Then I get there and ask if they’ve got a quiet room. Sometimes it’s yes, sometimes it’s yes but it’s not actually a quiet room, and sometimes it’s just no."
Autistica and the Alan Turing Institute have partnered to create a citizen science initiative exploring how autistic people navigate environments they find difficult. At present, the funding and potential reach of this platform is limited. Public research funders such as UK Research and Innovation and National Institute for Health Research should consider providing funding to expand the citizen science programme to provide further insight into different areas of public life. Employers, GP practices, schools, Jobcentre Plus services and other local public services should consider encouraging people to become citizen scientists and share their own experiences. Individuals who wish to take part should sign up to the project mailing list for updates.

The citizen science project will help build an evidence base about how to make environments more accessible to different groups of autistic people. When data becomes available, Primary Care Networks, hospital trusts, local authorities and other public services should apply for access and ask their own research questions to gain insight into improving their own environments.

The “priority challenges for action” underpinning the most recent Adult Autism Strategy in 2014 included: “I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am.” Rather than implementing one idea of ‘autism-friendly’, we now need to focus on finding out what works for different groups of autistic people.

The Government’s next Autism Strategy should encourage all Government departments and public sector bodies to join the citizen science initiative and help build our understanding of how to support the diverse needs of autistic people.

The sensory barriers facing autistic people may not always be obvious. Sustainability and Transformation Partnerships, Integrated Care Systems, local authorities and others involved in planning public services should work with autistic people to carry out regular sensory audits of their own environments as part of wider assessment of accessibility for autistic people. This should then be compared against initiatives such as the citizen science project and Ask, Listen, Do to account for the needs of a range of autistic people.
Eating disorders
Adult mental health


6 Autism (Unpublished). A survey of the autism community’s experiences with mental health services, conducted during Mental Health Awareness Week 2018.


Health checks

1 Autism (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.


Epilepsies

1 Autism (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.


Other co-occurring conditions

1 Autism (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.


Post-diagnostic support for adults

1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.


18 Kresner N and White S (2014) ASD in Females: Are We Overstating the Gender Difference in Diagnosis? Clin Child Fam Psychol Rev 17(1), 67-84. <ncbi.nlm.nih.gov/pmc/articles/PMC3836118>


Employment


Sensory needs and the built environment


7. Minister of State for Disabled People, Health and Work (2019). Written Answer to Parliamentary Question 24084. <bit.ly/2QJY1X1>