

Autistica Health Checks Plan

How to ensure every autistic adult is offered a yearly, tailored health check, by 2030

autistica

Stage 1: Building the evidence base

June 2023



Contents

Foreword	3
Why health checks	4
How to make breakthroughs	10
The price of success	11
Projects to enable breakthroughs—	12
Co-designing the optimal health check	13
UCL behavioural insights study: Informing policy priorities	15
An NHS England joint randomised controlled trial	17
Building the evidence base for health checks	18
Interactive workshops	20
Autistica policy commitments	21
Conclusion: A call to action	22
References	23

Foreword

James Cusack, Autistica CEO

When creating the NHS, the government made a promise to provide a healthcare system that “everyone – rich or poor, man, woman or child – can use and be part of.”

But autistic people are being left behind. They are struggling alone, suffering with treatable health problems when services should be helping, and dying earlier as a result. Together we can change that. And the NHS can stay true to its promise.

On average, autistic people die decades before non-autistic people.¹ Following a landmark Swedish study in 2016 which was one of the first to demonstrate these disparities,² Autistica took on the responsibility of highlighting these shocking findings to the government and the public.^{1,3} Evaluating the evidence around this was one of my first tasks upon joining Autistica. We have since spent years explaining that evidence to politicians, public servants, donors, and the wider scientific community.

Those efforts worked. In 2018, the Government refreshed their Autism Strategy to make closing the gap in life expectancy its overarching objective (the first time autistic deaths had been recognised in UK public policy).⁴ In 2019, the NHS in England made autism a clinical priority and adopted our vision of ensuring all autistic people “live happier, healthier, longer lives.”⁵ Later that year, NHS England partnered with us to co-fund the ground-breaking research project we had begun with support from autistic people and the Peter Sowerby Foundation: to co-design and test a health check that was tailored to autistic people’s needs.^{6,7}

Change cannot come too soon; the most recent analysis by NHS England shows that the mortality gap prevails, with data from 2020-21 showing autistic people in England had a mortality rate 51% higher than the general population, dying five years earlier.⁸

Together we’ve started to answer the question, but we haven’t yet delivered the promise. This plan sets out how we will do that. If, together, we succeed in delivering it, then we and the NHS will have kept that promise. We will have shown that autistic people’s lives do count and that we are willing to go that extra step in ensuring they are able to live them. The NHS’s promise is that “everyone...can use and be a part of” it. To do that, given what we know today, that also means ensuring that every autistic adult is offered a yearly, tailored health check.



A handwritten signature in black ink, appearing to read 'J Cusack'.

Dr James Cusack
Chief Executive, Autistica

Why health checks

The drivers of autistic health inequalities

Autistic people are at greater risk of experiencing poor outcomes from almost every health issue that has been studied.^{9,10}

Tragically, many autistic people needlessly die before their time. Autistic adults without co-occurring learning disabilities are nine times more likely to die from suicide, while autistic people with learning disabilities are at the highest risk of a range of physical health conditions. However, all people on the autistic spectrum face increased risk of illness and early death from a wide range of physical, mental and neurological conditions.²

The disparities are so profound that a 2022 study found that it was possible to predict if someone had an autism diagnosis or not, based on the types of health inequalities they experience.¹¹ So what causes these inequalities?

The interactions between individuals and the social context they live in may predispose some autistic people to illness

Although some autistic people appear to have a greater innate risk of developing conditions such as epilepsy¹² and hypermobility,¹³ all autistic people's health risks are **amplified by social determinants of ill health**. Autistic people are disproportionately affected by unemployment, poverty, abuse, trauma, and social stigma.^{14,15,16,17,18} For autistic people who are marginalised in other ways, such as those in ethnic minority communities and the LGBTQ+ community, this effect is compounded even further.^{19,20} Autistic people's health can also be affected by other complicating factors, for example diet, sleep problems and social isolation.

Appraising health and accessing health services is harder for autistic people

In many cases, autistic people face the same preventable health problems that affect the general population but can experience worse outcomes because they are **less likely to approach healthcare services or have successful interactions with them**. There are many complex reasons for this, including a lack of accessible communication options for contacting services and overwhelming sensory environments.^{21,22,23,24} These issues can lead to communication breakdown between autistic patients and healthcare providers.^{21,25}

Studies have found that issues around sensory environment, misinterpretation, healthcare navigation and difficulty following health advice affected autistic people **significantly more compared with people with other types of disability**.^{23,26}

Autistic people also report more difficulties identifying and communicating health problems;^{11,23} this may be due to **differences in interoception**, the ability to sense bodily changes and know when something is wrong.²⁷ Recent NHS England data shows autistic people are less likely to attend screening appointments;⁸ this is another way detection of new problems may be missed.

Healthcare staff's responses to autistic people may inadvertently affect healthcare access and health outcomes

Healthcare providers report a lack of confidence and training around treating autistic people^{24,28} and may not have up to date knowledge about the health issues that frequently co-occur in autistic adults.^{24,29}

A recent YouGov poll commissioned by Autistica to launch the Autistica Attitudes Index found that there remains a high level of misunderstanding about autism in the general population.³⁰

Autistic people frequently report **negative stereotypes and misunderstandings** that impact their experiences of accessing healthcare.^{23,31,32}

Autistic people may be more affected by misdiagnosis and diagnostic overshadowing. This happens when a person's problems may be wrongly attributed to their autism and are not investigated as fully as they should be, but **illness and distress are not inevitable for autistic people and can and should be prevented.**

Sometimes, autistic people's poor outcomes are driven by a **lack of evidence** around treatments that are acceptable and effective for them.³³ Health providers are more likely to **prescribe antipsychotic medication to autistic people**, even when this is not needed or recommended³⁴ (such as for management of behaviour due to a lack of adequate support), which can have debilitating side effects that impact health outcomes and decrease life expectancy. Autistic people are more likely to spend time in psychiatric hospitals that often fail to meet their needs and can cause further distress and lead to poorer health outcomes.³⁵ Studies have also found autistic people are at **higher risk of illness and death from Covid-19.**^{36,37}

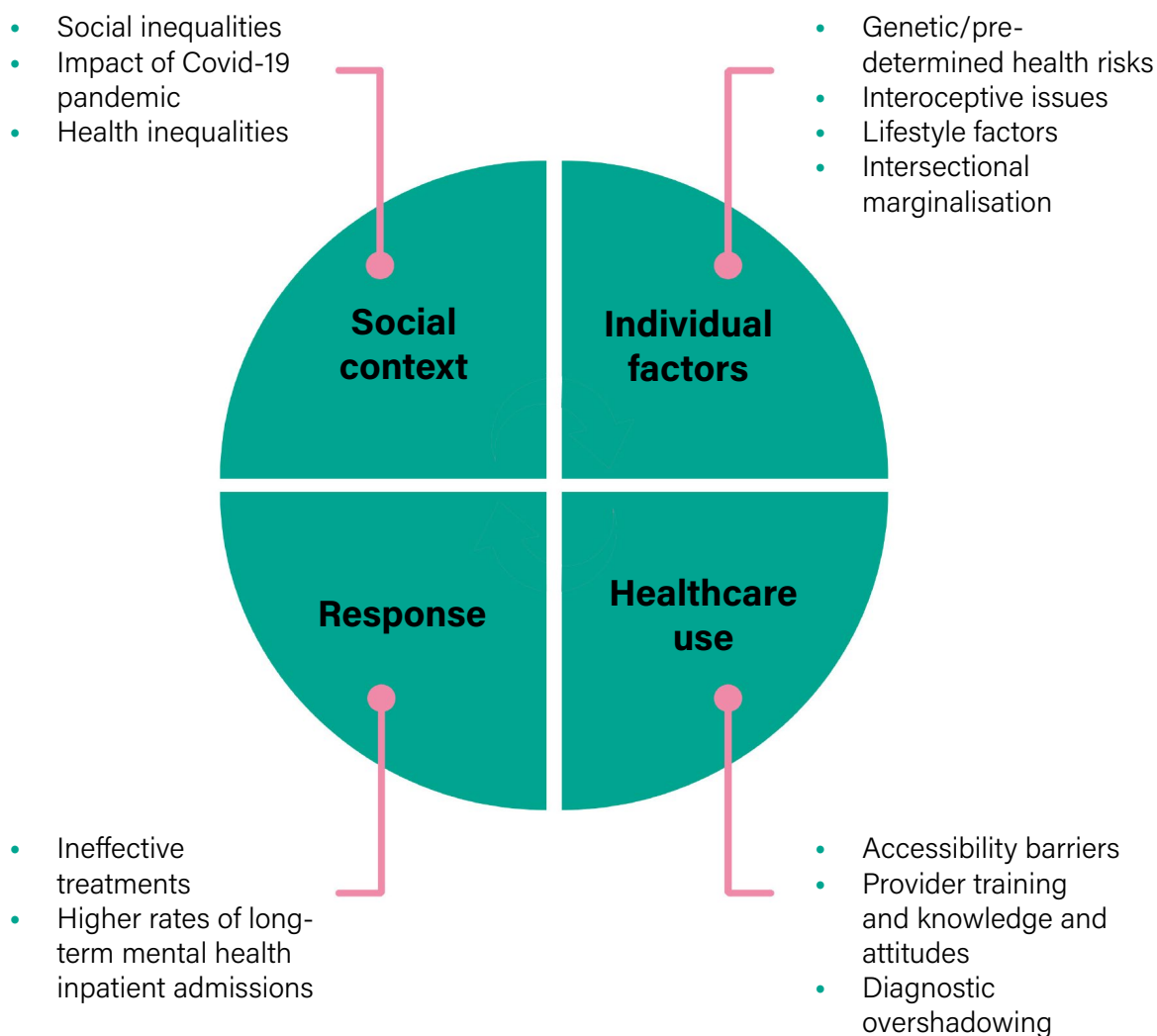


Figure 1. A complex combination of factors contributes to poorer physical and mental health in autistic people

Giving the NHS time to focus on autistic people



Autistica's Support Plan

For more information, see:
www.autistica.org.uk/about-us/2030/2030-support

The Autistica Support Plan sets out how to develop autism pathways that should act as the core of support for meeting autistic people's health and care needs. However, autistic people will need to rely on many healthcare services that do not specialise in autism through their lives. Leaving autistic people and families to fend for themselves in accessing mainstream healthcare is not working.

Services are starting to change in ways that will support autistic patients, with initiatives such as NHS Digital's reasonable adjustments flag,⁵ a new feature that will notify healthcare staff where patients have additional needs or require reasonable adjustments to their care, and follow patients through to all services they access. Further work in this area is to be welcomed, with Autistica committing to making public spaces more accessible for autistic people as one of our 2030 Goals. However, this can never be a complete solution – access needs across the population vary widely and sometimes clash, and not all autistic people will know or be able to articulate the specific adjustments they need. For various reasons, some will not contact health services at all unless prompted and around 4% of autistic people report being entirely excluded from healthcare.²²



"For me, sitting in a doctor's surgery is like sitting in a black hole where I am not allowed to move until my name is called. Needless to say, I do not go to the doctors even when I am ill. But I would go if I received a letter telling me that I had an appointment."

Autistic adult from Autistica's Briefing on health checks¹

We want to make it easier for the NHS and for autistic people to pro-actively manage healthcare needs by introducing an **annual health check for all autistic people** – a yearly review of existing conditions and medications. This will provide an opportunity to identify and address any new or continuing health problems that may need medical attention or referral to secondary care.

Autistica's long-held commitment to this goal has driven policy in this area. In 2016, the Westminster Commission on Autism, of which Autistica is a member, investigated inequalities in healthcare access faced by autistic people. It identified the development of an annual health check as a key recommendation.²⁴ Autistica has continued to press government bodies towards committing to this recommendation, and the development and testing of the autism health check has now been adopted as part of the Department of Health and Social Care's Autism Strategy,³⁵ the NHS Long Term Plan⁵ and an NHS England priority for autism research.³⁸

Health checks will give primary care protected time and resources to focus on autistic people's healthcare and accessibility needs. They also give autistic people an expected appointment to plan around to reduce uncertainty and stress, and bypass the need to pro-actively make an appointment, a task which some autistic people find impossible when in physical or emotional distress.

To reduce the costs to the health service and ensure a better quality of life for autistic people, more effort is needed in preventative care to detect problems in the early stages.

The health check is not just about physical health but is based on a **biopsychosocial** model focused on all areas of priority identified by autistic people, who have been involved throughout its development. The aims of the health check include identifying unrecognised health conditions, screening and prevention, addressing living circumstances, mental health and social care needs. This document details how investment has led to development of a co-produced, tailored health check and the work Autistica will do to continue to support this goal.



“The whole system is based on the idea that you have to be in crisis to get help.”

Will Melbourne, before he died in 2020³⁹

The track record of other health checks

The NHS and Department of Health and Social Care have expressed commitment to lowering the gap in life expectancy, tackling causes of mortality, and building longer, healthier lives for autistic people.^{5,35}

Research on health checks is currently one of the few large projects in the pipeline that have a realistic chance of delivering serious progress towards those goals and have widespread support, including from autistic people.⁴⁰ Health checks are already being delivered for preventative care in other groups with poor health outcomes, increased risk of chronic conditions and low health activation. This includes people with learning disabilities and people with serious mental health conditions, who can receive these annually, while middle-aged to older adults can receive a health check every five years.⁴¹

The most similar health check to the proposed autism health check is the existing check for people with a learning disability. These checks have been shown to be acceptable to patients, cost-effective and able to detect multiple health conditions per person, ranging from mild to serious health complaints.⁴² Studies and reviews of services have shown that detection of problems using health checks has led to health gains for people with learning disabilities. These include a significantly lower risk of early death for people who received health checks compared to those who didn't, especially amongst people aged under 50 and for autistic people who also have a learning disability.^{43,44} Other gains include receiving treatment for detected conditions, easing of symptoms and less distress-related behaviour due to health issues being addressed sooner.⁴² Even the detection of milder health conditions can improve overall quality of life and prevent more costly treatment being needed later on.

Health checks also need to be sustainable in the context of a health service with growing demands on its resources and staff. Yet the NHS reported that almost three quarters of people on the GP learning disability register received a health check from their GP in 2020/21, despite pressures during the Covid-19 pandemic,³⁸ suggesting health checks are relatively feasible for GPs to carry out in standard practice. Work still needs to be done on improving identification of people who are eligible for health checks to support projects like Autistica's health checks goal.

Autistic people on the learning disability register should already receive a health check, but the most recent estimates suggest at least 60-70% of autistic people do not have a learning disability.^{45,46} This means that as a population which remains at high risk for mental and physical health problems compared to the general population, many autistic people miss out on this opportunity to have their health reviewed. Some GP practices are already piloting health checks for autistic adults.⁸ However, the autism health check will not be simply an extension of the learning disability health check. Autistica's co-produced programme of work has ensured the rigorous development of an autism health check tailored to the specific needs of all autistic people. High quality research will investigate its effectiveness so decisions can be made about which health check will be most appropriate for autistic people with learning disabilities to receive.

Healthcare accessibility: the wider context

Health checks will be more successful if the health service works to address the other underlying barriers to healthcare for autistic people which research has identified time and again. The Department of Health and Social Care's Core Capabilities Framework⁴⁷ sets out the values and behaviours autistic people should be able to expect when accessing healthcare, identifying key areas including:

- Health professionals' knowledge, understanding and attitudes about autism and the complexities of co-occurring conditions that may present differently in autistic people than other patient groups;
- Improved understanding of the risks and protective factors of health outcomes for autistic people across the lifespan;
- Better understanding of the long-term impacts of medication use in autistic people;
- Reducing communication barriers and adding more accessible access routes into health services, such as making changes to avoid reliance on phone-based booking systems;
- Management of anxiety and uncertainty, for example by keeping appointments on time where possible;
- Addressing sensory issues that present barriers for autistic people in healthcare environments.

We know there will be challenges, but we believe these are not without solutions. With the evolving picture of GP practice in the UK, we have opportunities to try new ways of delivering healthcare: an example is how quickly telemedicine was adopted during the Covid-19 pandemic. The positive response from GPs signing up to trialling the health check and beginning to offer autism health checks independently of widescale implementation shows there is enthusiasm for improving healthcare for autistic people.

Testing of the health check is being delivered in the context of changes to the NHS that aim to help people live happier and longer lives,⁵ including the new Oliver McGowan mandatory autism training⁴⁸ being co-produced with autistic people, which aims to ensure all professionals have a good understanding of autism and reasonable adjustments. The NHS is introducing a reasonable adjustments flag to ensure the support people need is recorded across the health service. New information dashboards will also track autistic people's outcomes and use of services across sectors of care.⁴⁹ The Department of Health and Social Care made £1.25 million available to ensure every Integrated Care System has a named autism and learning disability champion, and a named executive lead for autism and learning disability on every integrated care board.³⁵ The health service has become more aware of neurodiversity among both staff and patients in recent years, contributing towards a culture of inclusivity and understanding.



Making health checks work for autistic people

Implementation science suggests that successful health behaviour change, such as uptake of the autism health check, depends on addressing three factors that influence behaviour of providers and patients: capability, opportunity and motivation.⁵⁰ The evidence on learning disability health checks and preliminary findings from research on attitudes towards health checks among autistic people, their supporters and NHS clinicians towards health checks, has helped us anticipate the main areas that could represent challenges and opportunities for implementation. This is where we can focus our health checks work alongside our partner projects and existing work that is already ongoing, such as training, to ensure all autistic people who are eligible for the health check are offered one, as well as to maximise uptake and success of health check appointments.

Capability	<ul style="list-style-type: none"> Providers should feel they have the skills and knowledge needed to carry out health checks, including understanding autism and reasonable adjustments. Autistic people should be aware they are entitled to a health check, understand what it is for, are invited and are able to attend the appointment.
Opportunity	<ul style="list-style-type: none"> Services should have enough resources and staff so that health checks can be carried out as planned, including attending training. Systems should be in place to make the process as efficient as possible. Services should make adjustments so that autistic people get the best outcomes from the appointment and all their concerns are addressed. Services should make an effort to reach less visible autistic people including those who don't currently access healthcare or who are marginalised in multiple ways.
Motivation	<ul style="list-style-type: none"> NHS and care staff understand why autism health checks are important for addressing health inequalities and saving time and costs for services. They will not see the health check as a box-ticking exercise. Autistic people feel confident to attend the health check and feel they can trust services to provide the care they need.

By approaching the health checks goal from multiple angles, we can begin to address these needs, and make recommendations that put people at ease about having their health concerns addressed.

Autistica have chosen to focus our efforts on research to start with. By supporting and funding research using the most rigorous methods available we will start to develop a clear idea of whether health checks for autistic adults are feasible, effective at detecting new health problems and acceptable for autistic people and primary care providers. This will be a significant step towards building an evidence base – as this grows NHS England will be able to make decisions such as who may be eligible for the autism health check and how it could be funded.

How to make breakthroughs

By 2030, every autistic adult will be offered a yearly, tailored health check

The pipeline for developing a rigorous healthcare intervention

1

Developing tailored health checks – It is critical we get this right, to ensure the health check works for autistic people and the NHS. Evidence is growing on barriers to healthcare experienced by autistic adults, helped by Autistica-funded research at Newcastle University which systematically reviewed research on this²¹. Understanding the barriers and health inequalities faced by autistic adults can help establish what the focus of health checks should be and how health checks may best be adapted for use with autistic adults, including any additional training needed for professionals. Further consultation with the autistic and medical communities, and other key stakeholders, will be essential to developing an appropriate health check model.

2

Testing the health check - Our clinical research partners at Newcastle University and Cumbria, Northumberland Tyne and Wear NHS Foundation Trust have developed a prototype health check, with a trial of its clinical and cost-effectiveness running until 2024. If successful, the materials will be shared with primary care services via NHS England. A less successful trial would indicate where the health check materials may need modification or where research needs to take a different approach.

3

Implementing health checks - This stage is about ensuring the NHS is equipped to use the health check, once finalised from what is learnt through the research trials. We will work with commissioners and GPs to find out the best ways to embed health checks into day-to-day primary care practice. This includes exploring ways of improving recording of autism diagnosis on medical records to ensure all autistic people eligible for a health check are offered one, and automating the process to reduce hassle for patients and providers. We also need to make sure GPs, patients and everyone who supports them, understands that the autism health check is an important step towards reducing mortality and other health inequalities.

4

Improving the health check and preparing the health service for long-term delivery Part of the value of a health check is that it gives everyone involved (from doctor, to receptionist, to patient) a focal point, which increases the chances of 'getting it right'. However, we need to ensure that we remove any remaining barriers for providers and patients. A body of evidence from ongoing research which can demonstrate the best ways to improve uptake and quality of health checks will be essential to supporting the NHS and patients to get the benefits from health checks long-term.

By 2030...


Develop Tailored Health Checks	Implement Health Checks	Make Healthcare Appointments Accessible
Health checks will be co-designed and rigorously tested with autistic people, families and GPs	GPs will be prepared and resourced to deliver annual health checks to autistic adults on the NHS	GPs will be empowered to adjust appointments to suit each autistic person's needs

The price of success

This plan could unlock billions

Each year, vast sums of money are spent on care, support and interventions for autistic people, but autistic people still show poorer outcomes compared to other disability groups.³³ Support is often insufficient and only delivered at the point of crisis, leaving many with unmet needs and unable to participate in society the way they would like to. Adding in the resulting lost earnings and need for long-term support, the cost to the economy is estimated to be £32 billion a year.⁵¹

We believe we can save costs by investing in the health check as a preventative form of healthcare to avoid more costly and invasive crisis support and reduce the inequalities that go on to impact other areas of autistic people's lives. For this reason, the government has already given health checks for autistic people serious consideration. Autistic people who are healthy and have a good quality of life have a great deal to contribute to society, so it makes economic sense to continue supporting this goal.

Develop tailored checks		Investment needed
Co-design the optimal health check <i>Autism research with co-production at the core</i>		£1.2 million – <i>Already invested by Autistica and NHS England</i>
A joint randomised controlled trial <i>Building the evidence base for health checks</i>		
Develop the evidence base <i>Investment in research to build on existing evidence</i>		Investment from trusts and foundations and the NHS as research priorities are identified
Implement health checks		
A national commissioning agreement <i>Ensuring commitment to improving autistic health</i>		Delivery of health checks estimated at £200 per patient for the current model being piloted
Pre-appointment questionnaire <i>Enhancing communication between patients and professionals</i>		Developed by Newcastle University. NHS England considering a zero-cost option for integration of digital tools into current systems
Training and guidance <i>Supporting clinicians to understand their autistic patients</i>		Online training programme. If successful, delivery will be through Health Education England
Autistica policy commitments <i>Future priorities and actions for health checks</i>		£16,900 to be spent by Autistica on engagement workshops and campaigning

Projects Autistica has invested in	Over £500,000
Amount already invested by public bodies	Over £700,000
Projects requiring investment from public bodies	£200 million needed

Projects to enable breakthroughs

Co-designing the optimal health check

Autistica's health checks strategy started in response to our 2016 report on high rates of early death in autistic people,¹ which prompted considerable thinking around health inequalities and how these could be addressed. This led to an international priority-setting summit on health and wellbeing, including world-leading researchers, autistic adults, relatives and healthcare professionals, which identified designing and testing health checks as a top priority.⁷

Autistica launched a competitive grant process with generous funding from the Peter Sowerby Foundation, won by an impressive international consortium led by Newcastle University. They aimed not to simply extend the learning disability health check to autistic people, but to co-design and pilot a new autism health check tailored to be appropriate for all autistic adults. We also commissioned researchers at UCL to carry out a project on behavioural insights, looking into health provider and patient attitudes towards the autism health check to help understand the challenges and opportunities for implementation.

In 2019, the goal of development and testing of an autism health check was adopted into the NHS Long Term Plan⁵ and in 2020, NHS England partnered with Autistica and the Peter Sowerby to fund a health check pilot trial. In 2022, Autistica helped get health checks recognised as a priority for NHS autism research.³⁸



- Autistica mortality report published highlighting health inequalities and generating discussion
- The Westminster Commission on Autism made health checks a key recommendation



- Autistica held a global health and wellbeing summit with autistic adults, relatives, researchers and health professionals
- The summit identified designing and testing health checks as a top priority



- Autistica funded a competitive grant process for research to co-design and pilot the health check, awarded to Newcastle University



- The NHS Long Term Plan made a commitment to health checks for autistic adults
- Health checks research commenced



- NHS England joined as a partner on the health check study in preparation for randomised controlled trial



- UCL Behavioural Insights project completed
- NHS research demand signalling for autism highlights priority areas for further research



- Randomised Controlled Trial now underway

Autistic people, healthcare professionals and researchers have been involved throughout, from initial scoping of the idea at Autistica’s physical health and wellbeing summit through to our ongoing implementation planning. The grant was co-written and reviewed by autistic people, GPs and leading scientists from across the world; the competing proposals were evaluated by autistic people, relatives, researchers and clinicians from Autistica’s expert Scientific Review Panel. The health check funded by the Peter Sowerby Foundation and NHS England has been designed and delivered by Newcastle University’s collaborative consortium including autistic and clinical study team members (e.g. GPs).

Researchers will carefully study the feasibility of carrying out health checks, with a randomised controlled trial (RCT) underway to measure clinical and cost effectiveness, and the extent to which unmet health and social care needs are identified and addressed through the health checks. The health check trial would also include a health economic analysis to tell us how identifying previously unmet health needs could potentially improve an autistic person’s health related quality of life and increase their quality adjusted life years (QALY’s – the number of life years and the quality of a person’s life in that period, affected by an intervention).⁵² What happens next will depend on research findings, but where hurdles are identified, we will be prepared to work on solutions and support further testing. We are already working with NHS England to scope out barriers to implementing health checks for autistic adults and ways to mitigate these.

Newcastle University’s research and co-design work has identified autistic people’s health priorities and preferences that have been incorporated to create a biopsychosocial and truly tailored health check, going beyond physical health to include mental health, social support and access to services⁵¹ (Figure 3), which may help to develop an understanding of overall quality of life. This includes a one-to-one consultation with a clinician who has received specialist training who will help identify a suitable course of action to address any newly identified concerns – this could be a new medication, referral to a screening programme, psychological therapy, a social care referral or social prescribing opportunity. The trial will help to indicate how further research should establish if the Newcastle health check model is likely to be effective and acceptable.

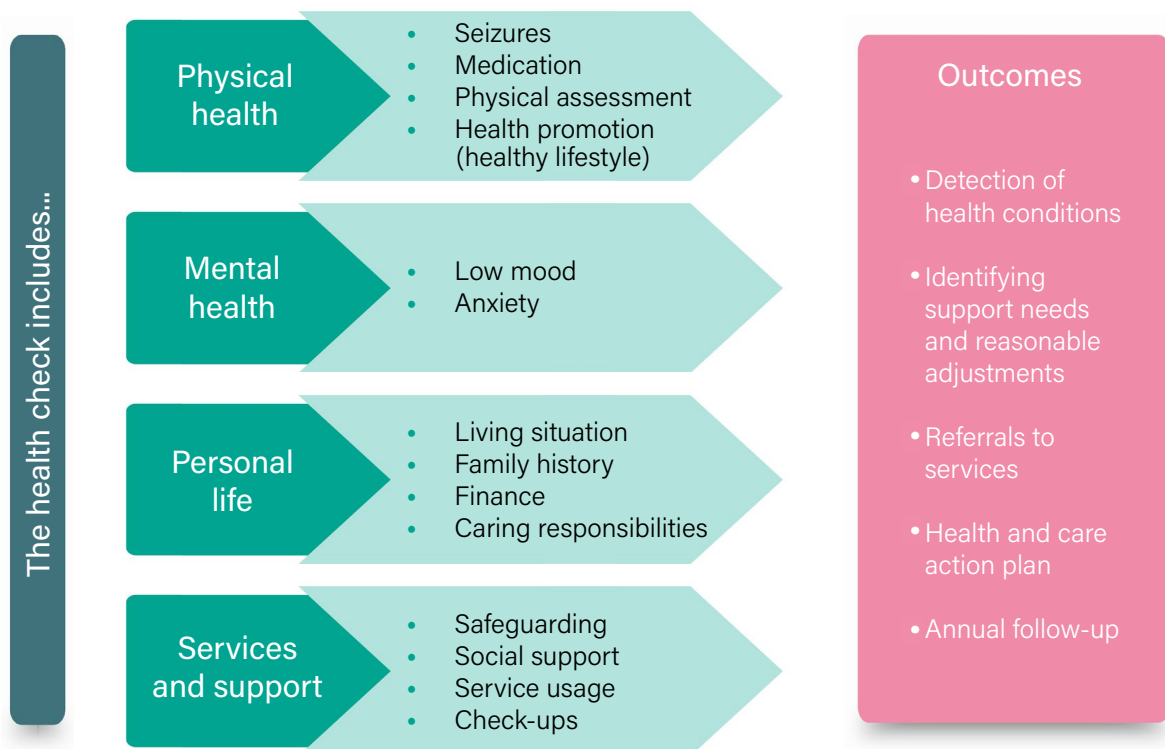


Figure 3. Examples of some components and potential outcomes of the trial health check

UCL behavioural insights study

Informing policy priorities

Why is this important? GPs and other primary care staff have extremely high workloads and experience many demands on their time, in the context of working for a health service experiencing a backlog from the pressures of the Covid-19 pandemic. Delivering health checks for all autistic adults is a difficult ask, but one that may ultimately save resources through preventing problems from escalating and reducing the need for more invasive crisis care. Research and consultation are needed to make the process as straightforward as possible and ensure that GP practices are supported in delivering health checks for all autistic adults to reduce mortality and health inequalities.

What is the current situation? Autistica commissioned researchers at UCL to carry out a behavioural insights study to investigate the attitudes of primary care professionals and autistic people towards the autism health check.⁵³ Responses highlighted funding and resourcing, such as staff shortages, as barriers to delivering the health check for autistic adults. Primary care professionals were also concerned about the frequency of having to deliver the health check annually for every patient. However, they were open to solutions to reduce time and effort in implementing the health check, and consideration of professionals other than GPs delivering health checks.

“This has to start with funding and resources [but] there’s no point funding it if we can’t recruit nurses and GPs to do the reviews. A review with a lesser trained person would probably be a pointless tick-boxing activity. Until general practice is better resourced it cannot take on more work.” - Healthcare professional

Professionals in the study did not always recognise the barriers autistic people faced when accessing healthcare. For example, they did not highlight communication as a barrier. Autistic adults thought professionals should receive more training on how illness and pain can look different for autistic people, to give professionals a better understanding of autism and common co-occurring conditions.

“[I] would need more information/training around specific issues affecting autistic people and advice on the best way to address these.” - Healthcare professional

Professionals welcomed the opportunity to receive more training on making their practice inclusive for autistic people. They also favoured the idea of having a dedicated expert member of staff to work with autistic patients and champion the health check scheme but noted this may only be feasible in larger practices.

The study led to 3 overall recommendations:

- Delegation of health check delivery, such as involving a variety of clinicians to carry out different parts of the health check
- Addressing funding and resourcing concerns by automating as much of the process as possible and building health checks into current commissioning structures
- Providing evidence on the importance and impact of health checks on autistic people and a rationale for the time frame

“Whilst I do not have to be persuaded that people with autism and LD need annual health checks, I would want to see evidence that there are clear benefits in terms of reduction in morbidity and mortality for health checks in the non-LD population as there are significant opportunity costs for the diversion of NHS time and resources to this group.” - Healthcare professional

Autistica has:

- Commissioned the behavioural insights study with primary care professionals and autistic adults, to understand the context surrounding health checks and the subjective barriers and enablers to delivering health checks.
- Continued to campaign and lobby for recognition of health checks as a priority for research and practice by policymakers.
- Held interactive workshops with key stakeholders to explore responses to the barriers and recommendations suggested by this research in the primary care context.

Autistica will:

- 1 Steer and monitor the evolving research landscape on health checks to evaluate the potential effectiveness and acceptability of different delivery models.
- 2 Build on evaluation to subsequently update our Health Checks Goal Plan, identifying ways to work towards implementation, consulting closely with NHS England throughout.
- 3 When the most effective model has been identified, we will develop a dynamic campaign, co-produced with autistic people, to encourage awareness of the importance of health checks among patients and healthcare professionals.
- 4 Continue to explore the development of healthcare toolkits for GPs and advocacy materials for patients
- 5 Support making reasonable adjustments to care for autistic patients.

Public research funders should:

- 6 Fund research to gather evidence on the best methods of delivery likely to be acceptable and effective for both healthcare providers and patients, making recommendations for alternative models where the evidence suggests these are needed.

An NHS England joint randomised controlled trial

High quality research is needed to meet NHS priorities for testing the uptake, quality, accessibility and adaptability of health checks,³⁸ and to make recommendations for their delivery within GP practice. The consortium at Newcastle University are using a randomised controlled trial (RCT), co-funded by NHS England, to test the success of their health check model for autistic adults. RCTs are the gold standard for research of this type. By enrolling GP practices and patients into either an active or control group, so that some deliver health checks to their autistic patients (active group) while others continue their usual care (control group), researchers can study the differences the health check makes to those who receive it, compared to those who do not. Practices are randomly assigned to groups, to ensure there are no other major differences between the groups other than who receives the health check. This is one of the largest rigorous scientific health care trials, to date, of a service-level intervention for autistic people.

- **Stage 1 – Completed:** Researchers carried out literature reviews, surveys and focus groups to identify barriers and facilitators to primary healthcare access and health checks for autistic adults.^{21,25,40,50}

Key Findings

- Over 70% of a large and diverse sample of autistic people thought a primary care health check is needed
- Over 80% said they would want to be contacted before the health check to provide information about their health needs and let their GP know what reasonable adjustments they would need
- Health professionals in the study were in favour of updating the healthcare offer for autistic adults and receiving additional training about autism in adults

- **Stage 2 – Completed:** Researchers developed the health check materials and a training package in collaboration with autistic adults, supporters and healthcare professionals.⁵¹

Outcomes

- Development of a pre-appointment questionnaire to be completed before the health check, including questions about access needs and reasonable adjustments
- A training package building on existing training with additional information about the health check, reasonable adjustments and the trial procedures

- **Stage 3 – In progress:** The randomised controlled trial aims to test if this type of health check is successful in identifying new health and care needs for autistic people, feasible for primary care practices to deliver and acceptable to healthcare providers and autistic people. Importantly, researchers will also make sure the health check is not causing harm to autistic people's health or quality of life. The trial also aims to find out if the health check is cost-effective for services and how it changes people's use of services. As trial data begins to be published over the next few years, this will start to build a picture of the effectiveness and feasibility of health checks for autistic people. NHS England will soon be able to start to make decisions about how the health check could be implemented in primary care practice across the NHS.

Other research and smaller localised projects are also being carried out, although this trial has the largest amount of funding for a project on health checks for autistic adults supported by NHS England. All research taking place in this area will be extremely valuable for building the evidence base which will inform the final model of autism health checks.

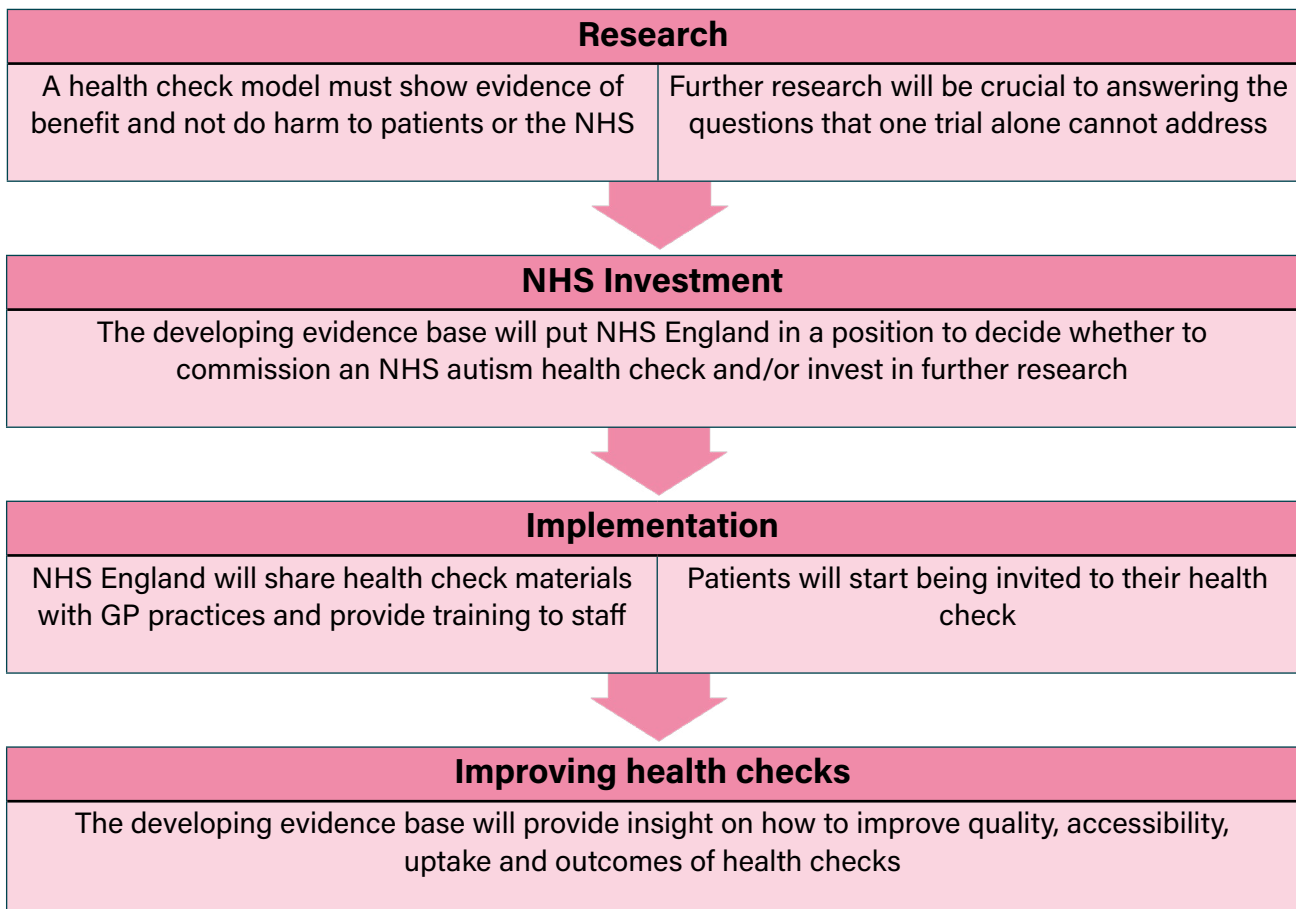
Building the evidence base for health checks

We recognise the extreme pressure the NHS is under and that the health service must make difficult decisions about which services to commission. Health checks will only be commissioned for the NHS if research can demonstrate good evidence that they can detect new health problems early, are feasible for GPs and are considered acceptable by autistic adults. An established body of evidence suggests this can be the case for annual health checks for people with learning disabilities. The trial will begin to answer these questions for the new health check for autistic adults.

However, the randomised controlled trial doesn't tell us:

- The long-term impacts of having a health check each year on autistic people's health or the NHS
- How the health check model that has been developed for the trial compares to other models in supporting the health needs and adjustments for autistic patients. For example, whether autistic people with learning disabilities might benefit more from this kind of autism health check or the pre-established learning disability health check.
- If the health check captures the needs of autistic people in underrepresented groups who may have less contact with GPs
- How health checks may work for people in residential or inpatient settings or the criminal justice system

These questions will require further research so that NHS England can continue to refine the health check and assess the value of further commissioning. This is a measured process and each step is dependent on the work that happens before it.



What if the trial doesn't find positive results?

Although Autistica and the NHS have put substantial investment into this research, we know that null results are just as important as positive results. Pushing ahead with an intervention that is ineffective, inefficient or a negative experience for autistic people could do more harm than good to autistic patients and the NHS. The health check will remain a commitment for Autistica and the NHS, but it's important we keep testing different approaches to find the right model and demonstrate real value for autistic people.

The funding for Newcastle University's RCT has helped researchers, the NHS and Autistica gather a vast amount of information on autistic people's experiences of accessing healthcare. It is also helping to inform health professionals' understanding of autistic people's healthcare needs. Autistica, NHS England and the government can use this information to continue educating and campaigning for better health care for autistic people across all sectors of the health service. There has been a high level of community involvement that has driven the development of a health check and training materials for the trial; these useful resources could be applied to other contexts or future research studies.



Interactive workshops

Working together on implementation priorities

NHS England, with input from Autistica, have identified some key areas of priority for strengthening the evidence base for the autism health check,³⁸ while Autistica's partnership with UCL led to recommendations for implementation to maximise health check acceptability for healthcare providers and patients. While the trial is underway, Autistica hosted online workshops in January 2023. These brought together different stakeholders, including autistic people, their supporters, health service commissioners and policymakers, GPs and researchers. People involved in the workshops have been giving us their views on how the issues affect them and may create barriers to delivering or accessing health checks. The groups have discussed solutions to help answer the questions that are not being directly addressed by the research trial.

Aims of workshops

- Consulting with the medical and autistic communities on issues that matter will help make sure that healthcare research, policy and practice will help autistic people feel confident to use health services and attend health checks, knowing that their needs will be understood and accommodated, whether attending independently or with a supporter and whatever the level of support needed. Workshops have gathered views and opinions to help commissioners consider the benefits and challenges of different delivery models and actions that could be made to support equitable health check delivery.
- We can apply for grants to support research, meaning if any ideas require further research we can find the best researchers and support them financially to achieve these aims.
- We want to campaign to help doctors and patients become aware of the importance of the health check – along with other changes such as training, accessible environments and communication.

Workshop topics

Reducing the workload for health check delivery

Autistica's goal: *Listen to suggestions from healthcare providers and patients on how to introduce more efficient systems and how to do this without compromising accessibility or quality for autistic people.*

Identifying who needs a health check and reaching underserved groups

Autistica's goal: *Advise decision-makers on adapting materials and procedures and to consider the most vulnerable autistic people a priority in delivery of health checks, to ensure no group is underserved or invisible. We want to build trust, agency and empowerment for autistic people around the use of diagnostic and health data in identifying who to invite for a health check.*

Finding out which health check models best support communication and accessibility needs

Autistica's goal: *Inform commissioners, GPs and primary care practices on accessible communication for autistic people and continue to campaign for more digital and remote options.*

Creating accessible information about health checks

Autistica's goal: *Co-produce campaigns and information to guide and motivate autistic people and GPs about the need for health checks and what to expect.*

Autistica policy commitments

Research and implementation priorities for health checks

- Completing the research trial
- Finding out the best models of health check delivery to maximise uptake, quality and consistency of health checks
- Building trust in the health check
- Supporting GPs to fit health checks into busy workloads
- Creating an efficient and ethical system for identifying and inviting all autistic adults to a health check
- Providing accessible information and communication options for autistic people and supporters
- Ensuring people who are vulnerable or marginalised can access health checks
- Investigating health check delivery in residential and secure settings
- Provision of impactful, coproduced training for GPs and other primary care staff who support health checks
- Ensuring autism champions in integrated care systems are knowledgeable about health checks
- Deciding on commissioning models
- Researching questions not answered by the current trial
- Assessing impact of health checks once underway

Autistica has...	Autistica will...
<ul style="list-style-type: none"> ✓ Made the case for health checks to the government so that a health check for autistic adults is now a goal of the Autism Strategy and NHS Long Term Plan 	<ul style="list-style-type: none"> » Consult with a range of autistic adults, supporters, healthcare professionals and commissioners to ensure any future delivery of health checks is accessible for patients and doesn't leave any group underserved or invisible
<ul style="list-style-type: none"> ✓ Secured funding which has supported researchers to coproduce and pilot a prototype health check, pre-appointment questionnaire and training package 	<ul style="list-style-type: none"> » Support with securing funding for further research to build on the existing evidence base by engaging with trusts and foundations
<ul style="list-style-type: none"> ✓ Worked with NHS England to develop our health checks plan and inform future research and implementation priorities 	<ul style="list-style-type: none"> » Continue to work with NHS England to explore, trial, develop and test feasible solutions to a tailored health check for autistic people
<ul style="list-style-type: none"> ✓ Gathered behavioural insights into barriers to health checks for GPs and patients to inform coproduction workshops 	<ul style="list-style-type: none"> » Help to coproduce patient information and campaigns focused on helping autistic people make informed choices and advocate for their needs in healthcare » Lobby the government to continue to tackle health inequalities affecting autistic people

Conclusion

A call to action

Improving health outcomes for autistic people needs coordinated action from individuals, services and Commissioners. Autistica has helped drive the conversation on health checks to make this a serious consideration by government and fund cutting edge research that aims to bring real benefits for autistic people's health, including reducing early mortality. We understand the value of consulting with autistic people and their supporters at each step to ensure our work has been led by community priorities. By working together with NHS England, the Department of Health and Social Care, and researchers, we have set out our goal for continuing to develop and test a health check for autistic people. This plan will take us up to 2025, at which point we will review the progress and evidence for health checks in autistic adults and their suitability for NHS delivery. We'll work with stakeholders to co-develop an implementation plan setting out how we will support health check delivery. This could include funding further research, coproducing patient information and campaigning to raise awareness of the health check.

We can't achieve our goals alone. We need funders, advisors and champions to make change happen. If you can support this goal in any way, please get in touch. Contact research@autistica.org.uk for research enquiries and info@autistica.org.uk for all other enquiries.

About Autistica

Autistica is the UK's leading autism research and campaigning charity. Our vision is a world where every autistic person lives a happy, healthy, long life.

Our mission is to create breakthroughs by funding research, shaping policy and working with autistic people to make more of a difference.

Our Goals: by 2030...

All autistic people will have proven support from day one

Public spaces will be more accessible for neurodivergent people

The employment rate for autistic people will double

Every autistic adult will be offered a yearly, tailored health check

All autistic people will have proven treatments for anxiety

Attitudes to autistic people will change

References

- 1 Autistica. 'Personal Tragedies, Public Crisis: The Urgent Need for a National Response to Early Death in Autism' London, UK: Autistica, 2016. <https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf>
- 2 Hirvikoski, Tatja, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, and Sven Bölte. 'Premature Mortality in Autism Spectrum Disorder.' *The British Journal of Psychiatry* 208, no. 3 (March 2016): 232–38. <https://doi.org/10.1192/bjp.bp.114.160192>
- 3 Howell, Dominic. 'People with Autism "Die Younger"', Warns Charity' BBC News, 18 March 2016, sec. Health. <https://www.bbc.com/news/health-35833997>
- 4 Autistica. 'Government to Make Early Death Top Priority for Autism Policy.' Autistica, 5 April 2018. <https://www.autistica.org.uk/news/government-make-early-death-the-top-priority-for-autism-policy>
- 5 National Health Service. 'The NHS Long Term Plan' National Health Service, January 2019. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- 6 Autistica. 'Could Yearly GP Checks and Changes to Appointments Improve Health?: Design and Initial Evaluation of an Autism-Specific Health Check for Use with Autistic Adults in NHS Primary Care.' Autistica, 31 May 2019. <https://www.autistica.org.uk/our-research/research-projects/health-checks>
- 7 Warner, Georgina, Jeremy R. Parr, and James Cusack. 2019. 'Workshop Report: Establishing Priority Research Areas to Improve the Physical Health and Well-Being of Autistic Adults and Older People.' *Autism in Adulthood* 1 (1): 20–26. <https://doi.org/10.1089/aut.2018.0003>
- 8 Townsend, Emily. 2022. 'NHSE Estimates Mortality Rate for Autistic People Is 51pc Higher.' *Health Service Journal*, December. <https://www.hsj.co.uk/mental-health/nhse-estimates-mortality-rate-for-autistic-people-is-51pc-higher/7033797.article>
- 9 Croen, Lisa A, Ousseny Zerbo, Yingge Qian, Maria L Massolo, Steve Rich, Stephen Sidney, and Clarissa Kripke. 'The Health Status of Adults on the Autism Spectrum.' *Autism* 19, no. 7 (1 October 2015): 814–23. <https://doi.org/10.1177/1362361315577517>
- 10 Bishop-Fitzpatrick, Lauren, Arezoo Movaghar, Jan S. Greenberg, David Page, Leann S. DaWalt, Murray H. Brilliant, and Marsha R. Mailick. 'Using Machine Learning to Identify Patterns of Lifetime Health Problems in Decedents with Autism Spectrum Disorder.' *Autism Research* 11, no. 8 (2018): 1120–28. <https://doi.org/10.1002/aur.1960>
- 11 Weir, Elizabeth, Carrie Allison, and Simon Baron-Cohen. 'Autistic Adults Have Poorer Quality Healthcare and Worse Health Based on Self-Report Data.' *Molecular Autism* 13, no. 1 (26 May 2022): 23. <https://doi.org/10.1186/s13229-022-00501-w>
- 12 Woolfenden, Sue, Vanessa Sarkozy, Greta Ridley, Michael Coory, and Katrina Williams. 'A Systematic Review of Two Outcomes in Autism Spectrum Disorder – Epilepsy and Mortality.' *Developmental Medicine & Child Neurology* 54, no. 4 (2012): 306–12. <https://doi.org/10.1111/j.1469-8749.2012.04223.x>
- 13 Csecs, Jenny L. L., Valeria Iodice, Charlotte L. Rae, Alice Brooke, Rebecca Simmons, Lisa Quadt, Georgia K. Savage, et al. 2022. 'Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain.' *Frontiers in Psychiatry* 12. <https://www.frontiersin.org/articles/10.3389/fpsy.2021.786916>
- 14 Brugha, T., S. McManus, H. Meltzer, J. Smith, F. J. Scott, S. Purdon, J. Harris, and J. Bankart. 'Autism Spectrum Disorders in Adults Living in Households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007. Leeds, UK.: NHS Information Centre for Health and Social Care, 2009. http://doc.ukdataservice.ac.uk/doc/6379/mrdoc/pdf/6379_apms_2007_autism_report.pdf
- 15 Office for National Statistics. 'Disability Pay Gaps in the UK - Office for National Statistics.' Office for National Statistics, 25 April 2022. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilitypaygapsintheuk/2021>
- 16 Trundle, Grace, Katy A. Jones, Danielle Ropar, and Vincent Egan. 'Prevalence of Victimisation in Autistic Individuals: A Systematic Review and Meta-Analysis.' *Trauma, Violence, & Abuse*, 6 May 2022, 15248380221093688. <https://doi.org/10.1177/15248380221093688>
- 17 Hughes, Rosemary B., Susan Robinson-Whelen, Dora Raymaker, Emily M. Lund, Mary Oschwald, Marsha Katz, Albert Starr, et al. 'The Relation of Abuse to Physical and Psychological Health in Adults with Developmental Disabilities.' *Disability and Health Journal* 12, no. 2 (1 April 2019): 227–34. <https://doi.org/10.1016/j.dhjo.2018.09.007>
- 18 Botha, Monique, and David M. Frost. 'Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population.' *Society and Mental Health* 10, no. 1 (1 March 2020): 20–34. <https://doi.org/10.1177/2156869318804297>
- 19 Bishop-Fitzpatrick, Lauren, and Amy J. H. Kind. 'A Scoping Review of Health Disparities in Autism Spectrum Disorder.' *Journal of Autism and Developmental Disorders* 47, no. 11 (1 November 2017): 3380–91. <https://doi.org/10.1007/s10803-017-3251-9>
- 20 Hall, Jean P., Katie Batza, Carl G. Streed, Brian A. Boyd, and Noelle K. Kurth. 'Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder.' *Journal of Autism and Developmental Disorders* 50, no. 8 (1 August 2020): 3071–77. <https://doi.org/10.1007/s10803-020-04399-2>
- 21 Mason, David, Barry Ingham, Anna Urbanowicz, Cos Michael, Heather Birtles, Marc Woodbury-Smith, Toni Brown, et al. 'A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults.' *Journal of Autism and Developmental Disorders* 49, no. 8 (1 August 2019): 3387–3400. <https://doi.org/10.1007/s10803-019-04049-2>
- 22 Doherty, Mary, Stuart Neilson, Jane O'Sullivan, Laura Carravallah, Mona Johnson, Walter Cullen, and Sebastian C. K. Shaw. 'Barriers to Healthcare and Self-Reported Adverse Outcomes for Autistic Adults: A Cross-Sectional Study.' *BMJ Open* 12, no. 2 (1 February 2022): e056904. <https://doi.org/10.1136/bmjopen-2021-056904>
- 23 Raymaker, Dora M, Katherine E McDonald, Elesia Ashkenazy, Martha Gerrity, Amelia M Baggs, Clarissa Kripke, Sarah Hourston, and Christina Nicolaidis. 'Barriers to Healthcare: Instrument Development and Comparison between Autistic Adults and Adults with and without Other Disabilities.' *Autism* 21, no. 8 (1 November 2017): 972–84. <https://doi.org/10.1177/1362361316661261>
- 24 Christou, E. 'A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People.' Huddersfield, UK: Westminster Commission on Autism, July 2016. https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf
- 25 Brice, Samuel, Jacqui Rodgers, Barry Ingham, David Mason, Colin Wilson, Mark Freeston, Ann Le Couteur, and Jeremy R. Parr. 'The Importance and Availability of Adjustments to Improve Access for Autistic Adults Who Need Mental and Physical Healthcare: Findings from UK Surveys.' *BMJ Open* 11, no. 3 (1 March 2021): e043336. <https://doi.org/10.1136/bmjopen-2020-043336>
- 26 Strömberg, Maria, Lina Liman, Peter Bang, and Kajsa Igelström. 2022. 'Experiences of Sensory Overload and Communication Barriers by Autistic Adults in Health Care Settings.' *Autism in Adulthood* 4 (1): 66–75. <https://doi.org/10.1089/aut.2020.0074>
- 27 Fiene, Lisa, and Charlotte Brownlow. 'Investigating Interoception and Body Awareness in Adults with and without Autism Spectrum Disorder.' *Autism Research* 8, no. 6 (2015): 709–16. <https://doi.org/10.1002/aur.1486>
- 28 Unigwe, Silvana, Carole Buckley, Laura Crane, Lorcan Kenny, Anna Remington, and Elizabeth Pellicano. 'GPs' Confidence in Caring for Their Patients on the Autism Spectrum: An Online Self-Report Study.' *British Journal of General Practice* 67, no. 659 (1 June 2017): e445–52. <https://doi.org/10.3399/bjgp17X690449>
- 29 Micali, Martina, Antonio Ciaramella, Tommaso Salvitti, Francesca Fulceri, Laura Maria Fatta, Luise Poustka, Robert Diehm, et al. 'Autistic Adult

Health and Professional Perceptions of It: Evidence From the ASDEU Project' *Frontiers in Psychiatry* 12 (2021). <https://www.frontiersin.org/article/10.3389/fpsy.2021.614102>

30 Cusack, James. 'Awareness Isn't Enough, We Have to Tackle Understanding' *Autistica*, 1 April 2022. <https://www.autistica.org.uk/blog/understanding>

31 Nicolaidis, C., Raymaker, D., McDonald, K. et al. Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *J GEN INTERN MED* 28, 761–769 (2013). <https://doi.org/10.1007/s11606-012-2262-7>

32 Hallett, S. & Crompton, C.J. (2018) Too complicated to treat? Autistic people seeking mental health support in Scotland. *Autistic Mutual Aid Society Edinburgh (AMASE)* www.amase.org.uk/mhreport

33 Howlin, Patricia. 'Adults with Autism: Changes in Understanding Since DSM-111'. *Journal of Autism and Developmental Disorders* 51, no. 12 (1 December 2021): 4291–4308. <https://doi.org/10.1007/s10803-020-04847-z>

34 NHS England. 'NHS England » Stopping over Medication of People with a Learning Disability, Autism or Both (STOMP)' NHS England. Accessed 9 May 2022. <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/?msclid=721fa7dbcf6811ec945a5339bfae51e2>

35 Department of Health & Social Care. 'The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026' GOV.UK, 22 July 2021. <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>

36 Krieger, Israel, Galit Erez, Orly Weinstein, Arnon Dov Cohen, and Dana Tzur Bitan. 'COVID-19 Morbidity Among Individuals with Autistic Spectrum Disorder: A Matched Controlled Population-Based Study'. *Journal of Autism and Developmental Disorders*, 8 July 2021. <https://doi.org/10.1007/s10803-021-05187-2>

37 Schott, Whitney, Sha Tao, and Lindsay Shea. 'COVID-19 Risk: Adult Medicaid Beneficiaries with Autism, Intellectual Disability, and Mental Health Conditions'. *Autism* 26, no. 4 (1 May 2022): 975–87. <https://doi.org/10.1177/13623613211039662>

38 Banks, Roger, Claire Dowling, James Cusack, and Alison Austin. 2022. 'NHS Accelerated Access Collaborative » Research Demand Signalling: National Learning Disability and Autism Programme' NHS England. 20 September 2022. <https://bit.ly/3ZGkrVn>

39 BBC News. 2021. 'Autism and Anxiety: One Man "Failed by the System"'. *BBC News*, 27 August 2021. <https://www.bbc.co.uk/news/av/uk-58334061>

40 Mason, David, Helen Taylor, Barry Ingham, Tracy Finch, Colin Wilson, Clare Scarlett, Anna Urbanowicz, et al. 'Views about Primary Care Health Checks for Autistic Adults: UK Survey Findings'. *BJGP Open*, 26 May 2022. <https://doi.org/10.3399/BJGPO.2022.0067>

41 National Health Service. 'NHS Health Check'. [nhs.uk](https://www.nhs.uk/conditions/nhs-health-check/), 26 November 2019. <https://www.nhs.uk/conditions/nhs-health-check/>

42 Robertson, Janet, Chris Hatton, Eric Emerson, and Susannah Baines. 'The Impact of Health Checks for People with Intellectual Disabilities: An Updated Systematic Review of Evidence'. *Research in Developmental Disabilities* 35, no. 10 (1 October 2014): 2450–62. <https://doi.org/10.1016/j.ridd.2014.06.007>

43 Kennedy, Natasha, Jonathan Kennedy, Mike Kerr, Sam Dredge, and Sinead Brophy. 'Health Checks for Adults with Intellectual Disability and Association with Survival Rates: A Linked Electronic Records Matched Cohort Study in Wales, UK'. *BMJ Open* 12, no. 4 (1 April 2022): e049441. <https://doi.org/10.1136/bmjopen-2021-049441>

44 White, A., R. Sheehan, J. Ding, C. Roberts, N. Magill, R. Keagan-Bull, B. Carter, et al. 2022. 'LeDeR Learning from Lives and Deaths – People with a Learning Disability and Autistic People'. London, UK: Kings College London. [leder-main-report-hyperlinked.pdf \(kcl.ac.uk\)](https://www.kcl.ac.uk/le-der-main-report-hyperlinked.pdf)

45 Kinnear, Deborah, Ewelina Rydzewska, Kirsty Dunn, Laura Anne Hughes-McCormack, Craig Melville, Angela Henderson, and Sally-Ann Cooper. 2019. 'Relative Influence of Intellectual Disabilities and Autism on Mental and General Health in Scotland: A Cross-Sectional Study of a Whole Country of 5.3 Million Children and Adults'. *BMJ Open* 9 (8): e029040. <https://doi.org/10.1136/bmjopen-2019-029040>

46 Christensen, Deborah L., Kim Van Naarden Braun, Jon Baio, Deborah Bilder, Jane Charles, John N. Constantino, Julie Daniels, et al. 2018. 'Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012'. *MMWR Surveillance Summaries* 65 (13): 1–23. <https://doi.org/10.15585/mmwr.ss6513a1>

47 Department of Health & Social Care. 'Core Capabilities Framework for Supporting Autistic People'. Department of Health & Social Care, 2019. <https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf>

48 The Oliver McGowan Mandatory Training on Learning Disability and Autism – elearning for healthcare e-lfh.org.uk

49 NHS England. 2022. 'Autistic People's Healthcare Information Strategy for England' NHS England. 21 September 2022. <https://www.england.nhs.uk/long-read/autistic-peoples-healthcare-information-strategy-for-england/>

50 Michie, Susan, Maartje M. van Stralen, and Robert West. 'The Behaviour Change Wheel: A New Method for Characterising and Designing Behaviour Change Interventions'. *Implementation Science* 6, no. 1 (23 April 2011): 42. <https://doi.org/10.1186/1748-5908-6-42>


51 Northern Ireland Assembly (2020). Select literature review: Autism and its economic costs. Briefing Paper No. 08/21. NIAR 258-20. [niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2021/finance/0821.pdf](https://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2021/finance/0821.pdf)

52 Health Analytics. 'What Is A Quality Adjusted Life Year (QALY)? - Health Analytics'. Health Analytics (blog), 14 March 2022. <https://www.healthanalytics.com/expertise/what-is-a-quality-adjusted-life-year-qaly/>.



autistica

autistica.org.uk



Autistica
Suite B
6 Honduras Street
London
EC1Y 0TH

T 020 3857 4340
info@autistica.org.uk
autistica.org.uk

Registered in England
Company No. 5184164
Charity No. 1107350