

# Autistica Support Plan

**autistica**

How to build a proven support system for autistic people by 2030



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# Foreword

## *It's time to act*

### Why we chose this topic

We are focusing on improving post-diagnostic and ongoing support because autistic people have told us it is essential for ensuring they enjoy the happier, healthier, longer lives they have the right to. For years we have worked with autistic people and families to understand their priorities and find better ways of meeting these. Recently, we have begun working more closely with NHS England and the Department of Health and Social Care through partnerships and secondments to embed the breakthroughs made by research.

We've guessed away autistic people's lives for far too long. It is not OK to give someone a lifelong diagnosis, tell them their outcomes may be poor and then abandon them with little or no support.

Together we can do better. The last two years have shown how research can be mobilised to fight a pandemic, to develop life-saving tests, therapies, and vaccines for COVID-19 at scale and pace. If we can utilise science to build a support system that works for autistic people, we can redress many of the worst disparities in our society. We can ensure that autistic people and families feel empowered by a diagnosis. We can ensure autistic people's mental and physical health doesn't deteriorate into a crisis. We can prevent the tragic stories that have plagued our field. The status quo is financially, politically, and morally unacceptable. This plan is an opportunity to build a better future for autistic people.

### We can make breakthroughs

Autistica is the UK's leading autism research and campaigning charity. We make breakthroughs that enable autistic people and families to live happier, healthier, longer lives.

When I began my career as a researcher, research often fixated on questions that could not deliver the impact that autistic people and families need. Now, Autistica and other funders support hundreds of studies every year into the top community research priorities. Meaningful involvement practices, many of which I'm proud that Autistica helped develop, are no longer rare but are becoming standard practise across our field.

It took years for our warnings about early death in the autistic community to be heeded. Now, NHS England has a dedicated team, the first in its history, to tackle the health inequalities facing autistic people. A few years ago, when Autistica investigated issues like social care, epilepsy management, suicide prevention or post-diagnostic support, all we'd find were studies describing problems. Now we have research developing and testing solutions.

### A decade of change

We have laid the foundations for success, but we're yet to build on them. All that progress matters little if we can't use it to deliver real and lasting improvements to autistic people's lives. Together, we can create a future where every autistic person knows support is out there if they need it, where parents never feel helpless in the face of their child's distress.

**We've never been in a stronger position to improve autistic people's lives.** We have more effective processes for involving autistic people and families in decision-making. We have clearer and more ambitious policy commitments to enable public bodies to act. We have better evidence than ever before to help us design solutions that could really work.

### It's time for the hard work

**There are no shortcuts to reversing entrenched inequalities.** Many campaigners, governments, and organisations talk a good game about supporting autistic people, but nice sentiments and high ideals won't cut it. To make reliable progress, we need to be systematic and scientific. We need to pinpoint precisely why autistic people are systemically let down. We need to implement programmes of research to methodically tell us what works to address these inequalities. We need to provide services with the funding to put new evidence into practice.

**With this plan, Autistica is committing ourselves to doing the hard work.** This plan is a roadmap for transforming the support available to autistic people and families. In it, we describe a series of projects that we believe have the best chance of delivering effective change. Individually, each project is a chance to make a breakthrough in one part of the support pathway. Together, they are building blocks towards a support system that is organised, evidenced, and tailored to autistic people's needs.

### How this plan was co-developed

This plan is the culmination of a lot of work. Autistica's neurodiverse team have been scoping elements of this plan for years: exploring issues with autistic people, tracking evolutions in the evidence base, working with NHS England to understand operational requirements, and undertaking priority-setting exercises.

We brought together autistic people, parents, service leads, and researchers to review initial proposals for this plan. We then asked dozens of lived, professional, and scientific experts to help us refine drafts of it.

**The co-production will not stop here.** We need help to bring about change, to raise funds for the projects in this plan, and to help deliver them. As we progress and begin to test out ideas, we will learn more about what does and what does not work. As we learn more, we will look for opportunities to update and improve this plan.

### Principles behind this plan

We used three fundamental principles to decide on what to include and exclude from this plan.

1. Autistic people deserve support that is well evidenced. We cannot continue subjecting autistic people to interventions and service models that lack anything like the levels of evidence expected in other areas of healthcare. We must prioritise testing supports to ensure they are acceptable, effective and safe for autistic people. We've guessed away people's lives for far too long.
2. Support must be designed with autistic people and families to match their priorities. The proposals in this plan are designed around what autistic people have told us, directly and through dozens of research studies, they need at different points in their lives. Supports need to be adapted for different people, based on their needs.
3. Support must be realistic. There is no point demanding supports that cannot be maintained. We have worked with professionals to ensure the proposals in this plan are ambitious but achievable.



**Dr James Cusack**  
Chief Executive, Autistica

# The Cost of Inaction

## The current approach has failed

### There is no meaningful system of support

Autistic people should receive proven support from day one. At the very least, autistic people should be offered support that we know works from the day they are diagnosed. This support is key to autistic people thriving.

This has not happened. Autistic people, families and clinicians' biggest complaint about autism diagnostic pathways is the lack of support afterwards; that they feel abandoned with no hope<sup>1,2,3,4,5</sup> There is practically no guidance, nor resources, to help services and commissioners build consistent pathways. There have occasionally been national initiatives to improve elements of support, but they have lacked coordination, rigour, and ultimately impact.

**The signs of system failures are proliferating.** Government statistics on inpatient admissions, research papers on autistic people's outcomes, Care Quality Commission (CQC) reviews of autism care services, and coroner reports on autistic people's deaths all indicate that progress has faltered.

 **"The whole system is based on the idea that you have to be in crisis to get help."**  
Will Melbourne, shortly before he died in 2020<sup>6</sup>

### The impact on autistic people

Autistic people currently experience some of the worst disparities in our society.

- Autistic people dominate admissions to inpatient mental health settings.<sup>7</sup>
- Autistic people face the lowest known employment rate of any disabled group.<sup>8,9</sup>
- Autistic people continue to die decades before the rest of the population.<sup>10,11,12</sup>
- Stories of neglect and abuse in state-funded care have become so harrowingly common that scandals hit the headlines on a monthly, sometimes weekly, basis.

### The impact on the economy

By failing to support autistic people, we subject them to appalling outcomes that cost the UK economy a staggering amount every year – at least £32 billion on the best available models.<sup>13,14</sup> That is significantly more than comparable costs associated with high profile health issues, like cancer or heart disease.<sup>15,16</sup>

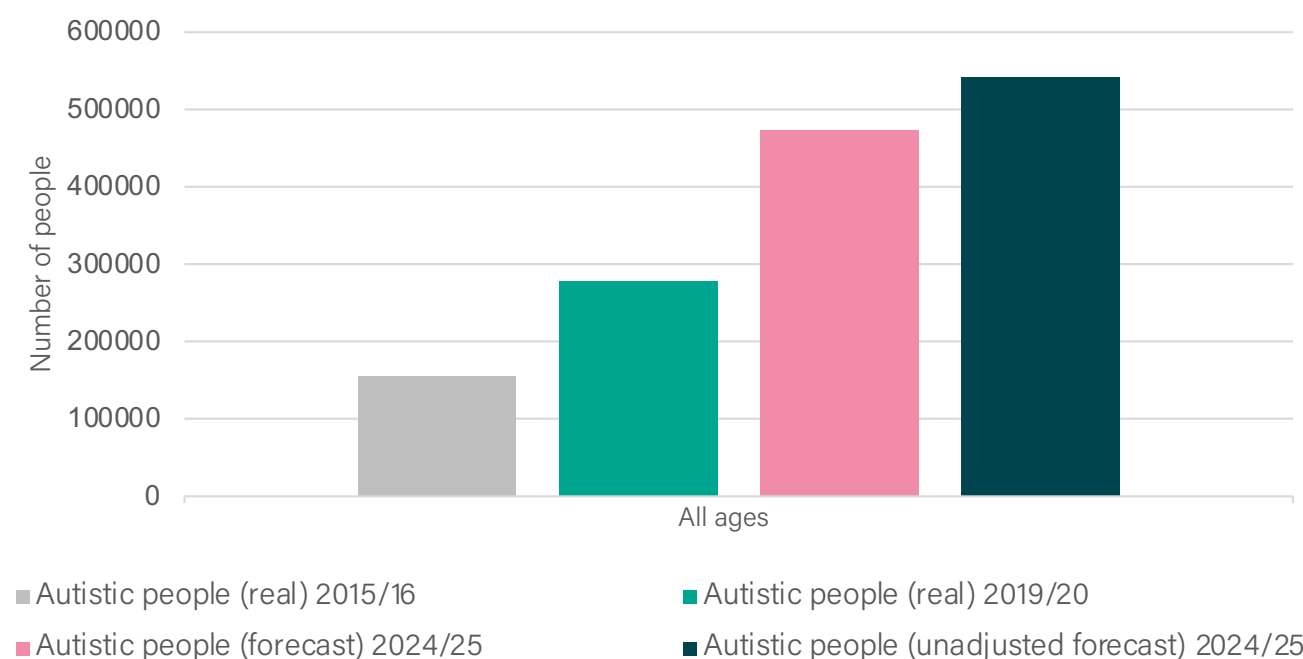
Most of these costs are not inevitable; they arise from failing to meet autistic people's needs before they escalate. The highest cost factors are lost productivity from autistic adults and parent-carers who are left unable to work, the cost of providing intensive social care to autistic people who were never enabled to live a more autonomous life, and the cost of providing invasive crisis healthcare to autistic people whose needs have become critical. We need to invest to save (in both lives and money).

### The impact on public services

We find far too many autistic people ending up in parts of the NHS and social care system where we don't want them to be. Autistic people are over-represented in secure mental health services, including inpatient eating disorder clinics, elective waiting lists and accident and emergency rooms. It is very difficult, and very expensive, to help people effectively if they require support in these circumstances. They are the parts of the pathway where poor outcomes are most likely and where NHS and Government policy commitments expect to see change. This isn't inevitable. The reason so many autistic people end up in acute, inpatient or crisis care is because we are not meeting their health and care needs effectively before they escalate.

These disparities look set to become even more apparent and system failures look set to become even more routine. We have become much better at recognising autistic people over the last couple of decades.<sup>17</sup> Even in the last five years, the number of autistic people known to NHS services almost doubled (see Figure 1).<sup>18</sup> However, services remain detached from autistic people's needs. **There has been a failure to resource health and care services to meet the demands placed on them and we have not prepared them for the increase that is coming.** The NHS Long Term Plan committed to ensuring that "all people with a learning disability, autism, or both can live happier, healthier, longer lives."<sup>19</sup> The NHS will need considerably more support to deliver on that promise.

Figure 1 – Adjusted forecast number of autism diagnosis in GP records



**Figure 1** – This table shows the number of NHS patients with an autism diagnosis recorded in their GP record over the last five years. These figures are from a sample of c.50% of GP records in England and so would need to be doubled to give an estimated number of diagnoses across the country. The dark green and pink bars forecast how those numbers are likely to rise by 2024/25 based on the trends over the previous four years. The pink bar is a more conservative forecast, which assumes the prevalence of autism diagnosis in each age group will never exceed 3.5% of the population.<sup>18</sup>

# A Better System

## Building world-class support

### The impact on the government

The government has made many promises to autistic people and families; to prevent abuse and neglect, reduce inpatient admission, improve diagnostic pathways, and finally level up support.

**Many of those promises have been heard over, and over, and over again.** They were heard in the first Autism Strategy; they were heard after Winterbourne View. They were heard in the second Autism Strategy; they were heard after Whorlton Hall. They were heard about the Transforming Care Programme; they were heard about the NHS Long Term Plan. They were heard after high profile death, after high profile death. Those promises have now been heard in the Government's new Autism Strategy, written more boldly than ever before. The new Strategy has a good vision. It's time for the Government to show the autistic community that they should believe what they hear. This plan is intended to help the Government fulfil its promises.

**"Our goal must be nothing less than making sure autistic people from all backgrounds, ethnicities, genders, sexualities and ages - in all parts of the country - get the support they need to live full and happy lives."**  
*The Rt Hon Sajid Javid MP, Secretary of State for Health and Social Care<sup>20</sup>*

Figure 2 – The gap in support for autistic people.



**Figure 2** – An illustration of the lack of pro-active support available to meet autistic people's needs. We predict that, as the number of recognised autistic people continues to expand, the number of autistic people seen in acute or crisis services will also rise. A meaningful support system for autistic people is needed to avert this.

**"The ideas in this plan have the potential to transform support for autistic people. The Government and NIHR need to join Autistica in doing their bit."**  
*Dr Carole Buckley, RCGP Representative for Autism*

**"How is this still happening in our system? We have known for some years about problems in the system...The big challenge is in part how to do that, and what the better system looks like... how do you get to that better system?"**  
*Helen Whately MP, then Minister of State for Care<sup>21</sup>*

## Our goal by 2030 is for all autistic people to have proven support from day one

### The stages of support

The types of support that will make the most difference to autistic people and families will vary at different points in their lives. Operationally, we recommend that public services consider support in three stages.

- #### 1 Support Understanding Autism

First, we should improve support for autistic people and families around and shortly after receiving a diagnosis. Receiving a diagnosis can be big news. All autistic people and their families should be empowered to understand their diagnosis and starts to come to terms with what being autistic means to them, personally.

We have no excuse for having ambiguous care pathways at this stage. Although experiences of being diagnosed differ, this is one of the most consistent and predictable parts of an autistic person's journey.
- #### 2 Support Preparing for the Future

Second, we should use the time after diagnosis to help autistic people and families prepare for the future. We need evidence-based systems that help match autistic people to the right therapies and services for their personal profile of needs. We need to connect people to safe, practical advice from peers who have been through the same everyday challenges they are facing.

Clear, evidence-based systems are what will make the difference at this stage. The diversity of autistic people's support needs has been taken as an excuse to allow a free-for-all. In an unguided melee, it is too easy for autistic people's needs to go unmet. If we don't have mechanisms for adopting new therapies or processes to ensure supports are evidenced, we cannot really claim to have a real support system.
- #### 3 Lifelong Support

Third, we need a feasible way of meeting autistic people's evolving needs, from early childhood to later life. Autistic people's support needs fluctuate over time and according to circumstances – an issue sometimes described in public services as "transitions". If we keep making autistic people and families fight to find support when they need it, we are inviting crises to happen. We need self-directed supports that can help autistic people and families to stay happy and healthy when they are doing well, and we need services that can step in and lighten the load when they start to struggle.

Support at this stage will only work if it can be realistically maintained. To make lifelong support viable, we need to nurture hubs of expertise in the NHS and social care systems, services that can deliver support directly and help other services to get it right.



Understanding autism	Preparing for the future	Lifelong support
Autistic people and families will be empowered to learn about their diagnosis and what it means to them.	Every autistic person will be offered proven supports tailored to their needs.	Every autistic person will have access to specialist support and tools to allow them to live a happier, healthier, longer life.

**“An autism diagnosis should not be the destination; but the start of a journey to better understanding, more accessible physical and mental healthcare, and appropriate support when needed throughout the lifespan to ensure we all enjoy the quality of life that we expect and deserve.”**  
*Colin Wilson, autistic researcher*

### Projects that would level up support

We believe that the projects shown below, and described later in this plan, have the highest likelihood of delivering breakthroughs; they are our ‘best bet’. Each project is based on discussions with autistic people, parents, healthcare professionals, and researchers about the most pressing gaps and how much evidence is available to indicate what might work. These projects are not exhaustive, but they are substantial. Together, they would deliver a better support system than any we know of, anywhere in the world, for autistic people. For decades, we have been failing autistic people. Through these projects, we have an opportunity to start succeeding.

Understanding autism	Preparing for the future	Lifelong support
Post-diagnosis empowerment programmes	Personal support profiles	Autism step-up services
Newly-diagnosed app	Everyday tips network	Self-directed supports library
NHS commissioning specification	New therapies launcher	Co-owned record system
Resource hub for professionals	Frameworks of interventions for supporting autistic people	Health checks for autistic people
	Trials fund to test supports for autistic people	

# The Price of Success

## The investments needed

### This plan could save billions

Even small improvements could make a massive difference. **If all the projects in this plan add up to only a 1% reduction in reliance on intensive long-term social care, or invasive crisis healthcare, then they would completely pay for themselves within a single year.** If the support created by this plan reduced those costs by 6.7% or productivity losses by 8.5%, then we could save over a billion pounds every year.<sup>22</sup>

Understanding autism		
Post-Diagnostic Empowerment Programmes	Essential interventions to ensure autistic people benefit from receiving a diagnosis.	£3.32 million £320,000 initial investment
Newly-Diagnosed App	App to complement post-diagnostic empowerment programmes.	£600,000
Professional Resource Hub	A single trusted source of resources for autism professionals.	£125,000 For 2022 to 2024
Commissioning Specification	Detailed guidance to provide direction to autism support pathways.	£200,000
Preparing for the future		
Personal Support Profile	Quality strengths/needs assessment to tailor care planning for autistic people.	£500,000
Everyday Tips Network	Crowd-sourced, quality-checked practical tips from the autism community.	£500,000
Intervention Framework	Guidance to address the free-for-all of interventions autistic people are subjected to.	£3.43 million
New Therapy Launcher	Fund to enable health care professionals to train in new therapies with the best evidence.	£35 million For 2022 to 2024
Trials Fund	Trial infrastructure to accelerate the development of new interventions and supports.	Up to £30.25 million
Lifelong support		
Autism Step-Up Services	Specialist services to be the cornerstone of a long-term support system.	£2.05 million
Self-Directed Support Library	Therapeutic tools that autistic people/ families can use themselves without public services.	£4.6 million
Co-Owned Record System	Shared record system to facilitate stepped care.	£540,000
Health Check Rollout	Evidenced checks to help autistic people manage their health needs.	TBC
Totals:	<b>Projects Autistica will invest in or partner on</b> <b>Projects requiring investment from public bodies</b>	£15.87m £65.25m

# Projects to enable breakthroughs

## Part I: Support Understanding Autism


It is vital that we help autistic people (and parents/carers) come to terms with their diagnosis, learn everyday tips, and have the chance to build a network with others in a similar situation. Without that support, we cannot ensure that autistic people benefit from being diagnosed.

**Quality is key.** Autistic people and families deserve the best information and advice. This is an opportunity to co-design and test support programmes that are acceptable, effective and can quickly be made available across the country.

# Post-Diagnosis Empowerment Programmes

## Essential interventions to ensure autistic people benefit from receiving a diagnosis

**Why is this important?** Receiving an autism diagnosis can be a pivotal time. There is clear scientific evidence that psychoeducation (support to understand and take ownership of a diagnosis) can be critical for ensuring autistic people benefit from receiving a diagnosis, as is standard practice in other health pathways.<sup>2,5,23,24,25,26</sup> Psychoeducation is also vital for challenging the stigma surrounding autism and improving the mental wellbeing of parents; both of which help ensure autistic people grow up in a supportive environment.<sup>27</sup> Scientifically proven and collaboratively designed psychoeducation should become a fundamental part of autism diagnostic pathways.

 **“Findings suggest that extended psychoeducation post-diagnosis is a critical element... This has revealed the negative impacts, which are potentially longstanding, that may occur as a result of inadequate psychoeducation support after diagnosis.”<sup>2</sup>**

**What is the current situation?** There are currently no psychoeducation programmes that have reliable evidence that they are effective for autistic people. However, there are promising support programmes (interventions) with the initial evidence of being feasible to provide and acceptable to those receiving them. Large-scale trials on these models have a good chance of identifying effective programmes. If those interventions are fully manualised, it will be much easier for other areas of the country to use them. For example:

For autistic children and their parents

- *EMPOWER* – A full randomised controlled trial (RCT) called REACH-ASD is already underway to establish the feasibility, acceptability, clinical effectiveness, and cost-effectiveness of the EMPOWER programme. EMPOWER is a psychoeducation+ programme for the parents/carers of autistic children up to 15 years.<sup>28</sup>
- *Other relevant interventions* – There are other post-diagnostic interventions which offer some form of psychoeducation to parents of autistic children and have evidence (or studies gathering evidence) of their acceptability and feasibility. However, none of these interventions yet have reliable evidence to demonstrate their efficacy.<sup>29</sup> The EPIC and SOLACE interventions provide different models of psychoeducation.<sup>30,31</sup> The EarlyBird and ASCEND programmes offer psychoeducation as part of a wider support model.<sup>32,33</sup> The ASTAR study tested a psychoeducation programme called Seven C’s of ASD to accompany the Predictive Parenting intervention for early co-occurring issues.<sup>34</sup> The SAFE and Riding the Rapids programmes provide some elements of psychoeducation but were designed and tested as interventions for co-occurring issues around distressed behaviour, and so are unlikely to be suitable as front-line post-diagnosis programmes.<sup>35,36</sup>

For autistic teenagers

- *PEGASUS* – In 2015, a pilot trial of the PEGASUS psychoeducation programme provided indicative evidence that it was acceptable and potentially effective.<sup>37</sup> A full trial of an updated PEGASUS model could provide a strong peer-led psychoeducation programme for autistic teenagers and their parents.

For autistic adults

- *SHAPE* – Recent findings from the SHAPE study suggest that psychoeducation programmes used by some specialist autism diagnostic services can improve the mental health outcomes of recently diagnosed autistic adults.<sup>2</sup> A follow-up study commissioned by NHS England is consulting with autistic adults and professionals on the core elements of an optimised psychoeducation programme. Trialling a manualised version of that new programme would help ensure that high-quality psychoeducation is available to autistic adults no matter where they live.
- *Older and Wiser* – A co-designed psychoeducation programme for autistic adults aged 55 and over recently demonstrated strong acceptability, although initial evidence of its efficacy was unclear.<sup>38</sup>



**“All too often diagnostic pathways for older autistic people are, in reality, diagnostic dead ends.”**

Colin Wilson, autistic researcher

### Autistica has:

- Funded the development of the SOLACE stigma protection intervention for parents of autistic children. Co-funded the development of the SAFE therapy for families following a diagnosis.
- Partnered with Kings College London and NHS England to identify the key features which autistic teenagers and clinicians want from a psychoeducation programme.
- Supported the University of York and NHS England to identify the key features which autistic adults and clinicians want from a psychoeducation programme and other interactions around diagnosis (like follow-up and debriefing appointments).
- Briefed the DHSC and NHS England about the evidence base for developing high-quality post-diagnostic information and empowerment programmes for autistic people.

### Autistica will:

- 1.1 **Fund the co-production of an optimised, manualised psychoeducation programme for autistic teenagers and families in preparation for a clinical trial.** It should address the needs of teenagers who were diagnosed earlier in life, as well as those who are newly diagnosed.
- 1.2 **Fund the co-production of an optimised, manualised psychoeducation programme for autistic adults in preparation for a clinical trial.**

### The NIHR needs to:

- 1.3 **Fund a fully powered RCT to determine the effectiveness of the optimised, manualised psychoeducation programme for autistic teenagers and their carers.**
- 1.4 **Fund a fully powered RCT to determine the effectiveness of the optimised, manualised psychoeducation programme for autistic adults.**
- 1.5 Consider funding clinical trials to establish the efficacy of other psychoeducation programmes for the parents of autistic children.
- 1.6 Consider funding the development and trial of an optimised, manualised psychoeducation programme for older autistic adults.



# Resource Hub for Professionals

## A single trusted source of resources for autism professionals

**Why is this important?** Scientific evidence should help services find ways to improve support. However, there is a worrying disconnect between autism research and practice. Historically, autism research has failed to address the priorities of autistic people using services or healthcare professionals delivering them. That pattern is changing, but our field still has limited success embedding scientific progress into the real world.

**“GPs simply don’t have the time to see all their patients and read every new scientific paper that comes out. Having the latest evidence in one reliable place could make a massive difference to the support we can offer autistic people.”**  
*Dr Carole Buckley, RCGP Representative for Autism*

**What is the current situation?** Healthcare professionals and commissioners do not have time to trawl through hundreds of academic publications every week and distil useable breakthroughs from experimental findings. Chances to transform lives are wasted because breakthroughs take too long to spread into practice. Research on manualised information and empowerment interventions should create optimised programmes that can be implemented quickly and consistently in different services. However, clinicians need to know about and be able to access those manualised resources to use them.

**How do we make a breakthrough?** Busy professionals working in services that see autistic people need a trusted source to help them utilise the best scientific evidence. Resources can be easily updated and rapidly tested with clinicians and autistic people to confirm they remain acceptable through an online hub. A resource hub could:

- Share the NHS Commissioning Guidance for Autism Services, explain the Autistica Support Model, host the Framework of Interventions for Supporting Autistic People, and provide examples of local post-diagnostic pathways.
- Host the New Therapy Launcher and signpost to the manual and training for key interventions, like the post-diagnostic information and empowerment programmes.
- Provide access to the assessment tool used to develop Personal Support Profiles.
- Direct clinicians to other reliable resources from charities like the National Autistic Society.

### Autistica has:

- A track record of developing resources to help NHS clinicians and commissioners apply the latest evidence, including crisis services,<sup>39</sup> eating disorder services and new communication therapies.<sup>40</sup>
- The expertise and networks to identify new scientific evidence which supports autistic people’s priorities and is ready for implementation.

### Autistica will:

- 2.1 **Develop an online autism post-diagnostic resource hub for professionals** that distils the latest scientific evidence into a single suite of resources for support around and after an autism diagnosis.
- 2.2 **Seek funding for an evidence manager to maintain the quality of information on the hub.** The manager could also help oversee the practical tips network and new therapy launcher.

### The government and the NHS need to:

- 2.3 **Provide modest funding to maintain the autism resource hub for public services.**
- 2.4 **Convene an expert advisory group to oversee the hub and new therapy launcher.** Autistica’s Evidence Manager could help operationalise this groups advice.





# Commissioning Specification for Autism Services


## Detailed guidance to provide direction to autism support pathways

**Why is this important?** Research shows that disjointed pathways can have a significant impact on autistic people's outcomes.<sup>2</sup> The lack of clarity and direction over how specialist autism services are funded beyond conducting diagnostic assessments is a critical problem.

 **"Both parents and adults expressed dismay at the general lack of appropriate support following the diagnosis."**<sup>1</sup>

**What is the current situation?** Autistic people, parents and clinicians consistently report that the lack of quality support after diagnosis is the biggest problem with autism pathways.<sup>1,3,4</sup> For the most part, funding is not in place to make this support properly available. Some areas do not have any established services for autistic adults. Others provide psychoeducation as part of their autism pathway, but this is the exception rather than the norm. Commissioners are given little direction on what they should expect to fund.

The alarming rates of autistic people ending up in inpatient care, A&E services or other parts of the public safety net illustrate that the status quo is not working. Services should be based on scientific evidence about autistic people's needs and what is effective in meeting them. People's health should not rest on the capacity of an individual commissioner to cobble together services from whatever evidence they happen to find.

 **"We're put under increasing pressure not to offer significant post-diagnostic support because of the multiple pressures on our service."**<sup>1</sup>

### Autistica has:

- Helped NHS England prepare guidance for investing new transformation funding into local autism diagnostic pathways.
- Sought expert epidemiological advice on the prevalence rates that should be used in commissioning. There is concern the conventional 1.1% rate is a misleading rate to use for commissioning arrangements and may be exacerbating the underfunding of services supporting autistic people.

### The NHS needs to:

- 3.1 Run or fund a project to understand what information local commissioners currently use and what other information may be useful** to decide on funding of autism diagnostic and post-diagnostic pathways.
- 3.2 Write a detailed commissioning specification for post-diagnostic autism pathways.** The specification should set out which pathway components should be standard, like the format of personal support profiles, and which can be varied. It should be clear on the functions that multidisciplinary Specialist Autism Teams, and other teams involved in diagnosing and supporting autistic people, must be funded to provide. Autistica is willing to assist with this work if desired.

**3.3 Set out how they intend to address the lack of candidates available to fill vacancies within autism services. To start, Health Education England should significantly increase the number of clinical psychology placements they fund** and should require more of those placements to specialise in neurodevelopmental conditions. Many services have been unable to recruit for years.<sup>41</sup> At the same time, clinical psychology placements remain massively over-subscribed.<sup>42</sup> The NHS desperately needs Health Education England to address this blockage and those for other roles in a multidisciplinary team (MDT) for autism, such as Speech and Language Therapists and Occupational Therapists.

**3.4 Establish an expert working group of epidemiologists to advise on pragmatic prevalence rates** for commissioning different parts of the post-diagnostic pathway, based on the live data about demand. These rates should be used to rapidly correct the misleading "population calculator" published in 2021.

**3.5 Improve the quality and completeness of population-level data on key components of autism diagnostic and post-diagnostic pathways.** For example, NHS Digital should collect and publish anonymised population-level statistics on the number of autistic people who have a Personal Support Profile. This will enable service improvement drives and ensure trends in service use, demographics, and outcomes are detectable.

### The government needs to:

**3.6 Provide significant funding through the next Spending Review for the NHS to commission post-diagnostic autism pathways in line with the new service specification.**

**3.7 Ensure local authorities responsible for funding the social care and education for autistic people are engaged in the autism pathway commissioning specification.**



**"All too often diagnostic pathways for older autistic people are, in reality, diagnostic dead ends. An autism diagnosis should not be the destination; but the start of a journey... This plan sets out some ambitious but important steps to tackle barriers to accessing appropriate, evidence-based support at the time it is needed, rather than at points of crisis."**

*Colin Wilson, autistic researcher*



## Newly-Diagnosed App

### App to complement post-diagnostic programmes

**Why is this important?** Autistic people and families should have access to the best and latest information that could help them. A digital companion, developed to complement the information shared in empowerment programmes after diagnosis, could help reinforce the insights and knowledge autistic people gain at each formal session.

**What is the current situation?** Psychoeducation programmes need to carefully plan how they share content and organise sessions to avoid overwhelming people with too much information. However, some may want further insights, stories, and tips.

**How do we make a breakthrough?** Developing an app-based resource to complement post-diagnostic empowerment programmes could help maximise their impact. An app could help preserve the information received during group sessions for long-term use, provide additional information to those who want it (such as managing disclosure and their rights around adjustments), and expand the network of peers able to share their experiences.

#### Autistica has:

- A track record of co-developing smartphone apps that empower autistic people with the latest evidence.<sup>43</sup>
- Working knowledge of the most promising post-diagnostic empowerment programmes that may provide the basis for the App. For example, as part of the REACH-ASD trial, a series of resources have been collated into a web-based platform to complement the sessions of the EMPOWER programme.
- Plans to develop a citizen science driven Everyday Tips Network that would provide curated content for the App.

#### Autistica will:

- 4.1 **Fund the development and testing of an app for newly diagnosed autistic people**, in collaboration with autistic people, services and researchers leading psychoeducation trials. If the app is successful, further development could make it a companion for autistic people during the diagnostic process or as a source of long term support.



**“In this game-changing plan, Autistica have addressed the fundamentals of what autistic children, young people, and adults need to have coherent, well-focused and pro-active support from the earliest point. By getting these support structures in place from early on, this plan creates the opportunity to start the ‘autistic journey’ within society on the best possible footing.”**

*Professor Jonathan Green, University of Manchester, Manchester University NHS Foundation Trust*





# Projects to enable breakthroughs

## Part II: Support Preparing for the Future

Health services have the best chance to pro-actively improve an autistic person's life in the period shortly after diagnosis, when they are at their most visible to services that specialise in autism. We know which challenges autistic people are most likely to experience and increasingly have evidenced supports to prevent or mitigate those issues. We should be helping autistic people (and parents/carers) to prepare for the future.

Pathways may need to differ substantially for different age groups at this stage. Younger children are in a unique development window where developmental supports can help them build skills naturally. Autistic teenagers and adults are more likely than their non-autistic peers to have mental ill-health, like anxiety or depression, which may require immediate treatment to support their long-term wellbeing.

**We need to create order out of chaos.** Because autistic people can have such different needs, no single set of supports will work for all, which makes it much harder to organise public services effectively. The system needs a consistent way of planning support around an individual's profile of needs.

# Personal Support Profiles

## Quality strengths/needs assessment to tailor care planning for autistic people

**Why is this important?** Support for autistic people should be tailored to their individual needs and goals. In other areas of healthcare, a diagnosis usually tells professional exactly what supports that person should be offered. With autism, the diagnosis only provides part of that information. The support each person needs will vary widely, so few interventions will be universally appropriate for autistic people and families.

**What is the current situation?** Currently, the onus is on the autistic person/carer to navigate local services. Occasionally a clinician goes above and beyond to arrange support for someone, but they rarely have time to do so. Other services are not prepared for receiving autistic people, which makes every referral, adjustment, and intervention a potential point of failure. Ultimately, most autistic people end up having access to a very narrow and ad hoc set of supports that bear little resemblance to their actual needs.

**How do we make a breakthrough?** Constructing an accurate, holistic, and consistently formatted profile of a person's support needs would make post-diagnostic support more strategic. It would enable healthcare professionals to offer autistic people the supports (interventions) they are most likely to benefit from, rather than focusing on a generic offering that may be unhelpful.

If profiles have a consistent format, then different services can prepare for using them. This is critical, as autistic people may need support from various public services across the NHS, social care, education, and welfare systems. Adopting one profile could help break down the siloed bureaucracies that frustrate autistic people, families, and clinicians.

A tool assessing an autistic person's strengths and needs must be carefully designed to balance different requirements.

- The tool must enable autistic people and parents to be partners in the assessment so that their personal profile becomes a resource they own and can use to maximise their wellbeing.
- It must be ergonomic, so a range of services uses it consistently.
- It must also be nuanced enough to discourage superficial characterisations of a person's needs; for example, it should discourage the fixation on the presentation of issues (like distressed behaviour) at the expense of recognising their causes (like a source of physical or mental discomfort).
- It must be holistic enough to account for the variety of autistic people's strengths and difficulties.
- It should enable different assessments for autistic children, teenagers, and adults. Its utility for autistic people in long term care with high support needs must also be tested.
- Ideally, it will become possible to develop complementing support profiles for other neurodivergent groups. The siloed nature of neurodevelopmental pathways can prevent people from accessing support, particularly if they don't quite meet a diagnostic threshold or fall into multiple groups.
- It must consider contextual factors that could impact an autistic person's access to support.

All these factors will influence the protocols, format, and language of the assessment and which professionals should conduct them. A recent scoping review, commissioned by NHS England, indicates that no tools currently meet these criteria.<sup>44</sup> However, the review did identify initial tools that could be developed further to fulfil this purpose. In particular:

- ICF-Based Assessments – An international research programme (including studies with autistic adults, parents and clinicians) recently established holistic lists of issues that most often enable or disable autistic people, using the World Health Organisations ICF framework.<sup>45</sup> The scoping review for NHS England recommended adopting the ICF approach and concluded that an operationalised ICF-based tool is likely to be effective and more practical than existing assessment tools.<sup>44</sup> The Karolinska Institutet in Sweden is currently developing an operational assessment tool using the ICF lists.<sup>46</sup> A similar ICF-based tool was recently piloted successfully in Argentina.<sup>47</sup>
- SIC-C, SIS-A and CLASS – The NHS England commissioned scoping review also found that the Supports Intensity Scale Children's version (SIS-C), the Supports Intensity Scale Adult's version (SIS-A), and the Children's Leisure Assessment Scale (CLASS) had promising elements. However, the review concluded that the SIC-C and SIS-A took too long to administer and that the CLASS was limited by only being applicable to school-aged children.

### Autistica has:

- Helped NHS England commission a scoping review of possible strengths and needs assessments.
- Explored the use of the Karolinska Institutet's ICF Assessment Tool in UK public services.

### Autistica will:

- 5.1 Fund the adaption and piloting of the ICF Assessment Tool in NHS diagnostic and post-diagnostic services for autistic people. This same tool also includes strengths and needs assessments designed for people with ADHD.

### The government and the NHS need to:

- 5.2 **Consider funding the creation of strengths and needs assessments for neurodivergent groups.** We would strongly recommend creating assessments for use on the ICF tool platform, as it can easily incorporate similar assessments, and there are existing ICF sets for other neurodivergent groups.



# Framework of Interventions for Supporting Autistic People

## Guidance to address the free-for-all of interventions used on autistic people

### What we mean by 'interventions'


In healthcare, the word intervention is used to describe any action taken deliberately to improve someone's life.

Scientifically, "intervention" is a broad, neutral term that can refer to many types of actions. For example, giving someone a drug to prevent epileptic seizures is an intervention, as is making a change to someone's environment to reduce the sensory overload on them.

Autistica believes that the interventions used by services should be:

- Designed with the specific groups of autistic people or family members they intend to help, so they focus on outcomes that matter to them. This is vital for ensuring an intervention has the right **intention** and uses an appropriate **mechanism** for making a change. People sometimes disagree about what intentions and mechanisms are acceptable in different circumstances, which is why it's important that there are well-evidenced interventions for people to choose from.
- Tested in studies that reliably show they are: **feasible** (they can realistically be delivered), **acceptable** (the people receiving and making the intervention like them), **effective** (they consistently improve outcomes that matter), and **safe** (they rarely, if ever, cause harm).

**Why is this important?** Autistic people deserve supports that work. It is unethical, dangerous, and detrimental to expect much lower standards of evidence for interventions given to autistic people compared to those offered to people with other conditions. The impact of failing to ensure autistic people receive acceptable, effective, and safe supports for their needs is evident in the appalling outcomes that persist across the autistic community.

 **"The Jury made the following findings, in relation to matters which they found to be contributory to Sophie's death...The discontinuation of external therapies contributed to a feeling of anxiety and uncertainty...Introduction and effect of a regime perceived by Sophie to be akin to a 'boot camp'"**


*Coroner's report on the death of Sophie Bennet<sup>48</sup>*

**What is the current situation?** There is an unguided free-for-all. Clinicians, autistic people, and families have next to no useful resources to distinguish interventions with reliable evidence from those with poor quality or no evidence. As a result, unacceptable, ineffective or questionable interventions continue to be widely used, the need to gather evidence on promising interventions is obscured, and there is no clear route to implement breakthrough findings. The support autistic people and families receive is often influenced more by information biases, habits, and luck than evidence-based healthcare.

For physical health, NICE clearly states what interventions can (and should) be used to address specific indications, under what circumstances. However, NICE Technology Appraisal, Medical Device or Interventional Procedure Guidance does not extend to the complex interventions most often used to support autistic people. No other public bodies provide guidance with an equivalent rigour and function.


The NICE Clinical Guidelines on autism deliberately avoid specifying which interventions can and cannot be used, instead only referring to general features or groupings of interventions. This ambiguity, coupled with the decade-old structure of the autism guidelines, means they are no longer of practical use to clinicians trying to design or deliver a care pathway for autistic people.

Publicly-funded organisations in other countries, like the Australian Autism CRC, have published practical guidance on interventions for supporting autistic people.<sup>49</sup> There are systematic reviews and trial data we could use to co-produce a similar framework. That framework could distinguish interventions that have sufficient evidence to be used for specific needs from interventions that lack evidence but could be further trialled. It could also identify support needs that lack any suitable interventions and should be prioritised for research.

 **"The sheer volume of separately developed and named interventions, and the lack of coordination around this, is likely to hinder the identification of programmes appropriate for further evaluation and implementation in routine practice"<sup>50</sup>**


### Autistica will:

- 6.1 **Co-produce a list of crucial support needs (indications)** to prioritise intervention guidance on. Data from post-diagnostic strengths and needs assessments could help guide this work.
- 6.2 **Work with public funders to commission systematic reviews and meta-analyses of interventions for crucial support needs.**

 **"There is a pressing need for increased reflection and articulation around how intervention practices align with a neurodiversity framework and greater emphasis within intervention programmes on natural developmental processes, coping strategies, autonomy, and wellbeing."<sup>29</sup>**

### NICE needs to:

- 6.3 **Develop and maintain a framework clarifying which interventions should be used to meet critical support needs among autistic people.** This guidance could provide greater clarity to clinicians, improve transparency for autistic people and families and direct strategic investments into intervention research.
- 6.4 **Re-structure their clinical guidelines on autism to reflect new evidence about autistic people's most common support needs<sup>51</sup>** and provide greater clarity on how specific parts of the pathway should be provided.

 **"We can always rely on Autistica to clearly identify the barriers facing autistic people across their lives and set out the changes that we desperately need. This Plan is right about the breakthroughs we need to make. It is pragmatic, realistic, impactful and, importantly, grounded in research evidence and the priorities of autistic people and their families."**

*Dr Kathy Leadbitter, University of Manchester*



# New Therapy Launcher

## Fund to enable healthcare professionals to train in new therapies with the best evidence

**Why is this important?** Most therapies that are relevant to autistic people and families are “complex interventions”. This means there are multiple components to the therapy, some of which relate to the therapist, which could affect its impact. To properly deliver these therapies, health and care professionals need to be trained in the manual that is developed (and tested) with the intervention; they also need time to practice delivering it with supervised support.

**What is the current situation?** The NHS does not have an effective way to roll out new complex interventions. There is no clear route for health and care professionals to become aware of and practiced in delivering new supports that are being designed and tested to help autistic people. When professionals do learn the manual for a new intervention, they often have no time to become practised in it. Instead, they immediately have to return to a heavy caseload with limited ongoing support. As a result, the health and care systems struggle to evolve their offering to autistic people. To replace outdated practices with more effective, more acceptable, and better-evidenced supports, we need to invest in developing our workforce.

A central fund could ensure that a choice selection of the most promising and best-evidenced new therapies are rolled out effectively across the NHS, social care, and education systems. This Fund should cover the training costs for professionals to learn new manualised therapies and enable healthcare providers to backfill roles for a short time – while they focus on delivering the new intervention. Practised professionals would then be able to return to their Integrated Care Systems (ICSs) and embed new practices in local pathways.

### Example of an exciting new therapy ready for launching: PACT

The Paediatric Autism Communication Therapy (PACT) is a therapy where parents and therapists work together to identify how a child prefers to play, using video recordings. They then adapt their interactions with their child to match that style. Young children learn a lot of skills through play but may approach it in very different ways. PACT has shown that by supporting the alternative ways autistic children learn, we can help them build stronger social communication skills, help parents feel more empowered, and increase families’ resilience. The therapy addresses autistic people and families second-highest priority for autism research: finding “effective interventions to develop communication and language skills”.<sup>52</sup> It also embodies a more progressive approach to support that embraces autistic people’s differences and opposes attempts to ‘normalise’ or ‘mask’ atypical behaviour.<sup>29</sup>

Crucially, PACT has strong evidence that it is acceptable, feasible, and effective. PACT is currently one of the only early interventions directed at autistic children and families that has demonstrated efficacy through high-quality Randomised Control Trials.<sup>53,54</sup> Results from the initial trial prompted NICE to describe a generalised version of PACT in the list of “key priorities for implementation” of its Clinical Guidance for supporting autistic children.<sup>55</sup> The second PACT trial was awarded NIHR Signal Study status for its “high-quality design and relevance to UK decision-makers”.<sup>56</sup> Other trials have since replicated evidence for its mechanisms in different age groups, countries and service contexts.<sup>57,58,59,60,61,62</sup>

PACT is ready for use, and accredited training for it is immediately available.<sup>63</sup> Both the therapy resources and training for PACT have recently been digitalised for online delivery. An adapted version of PACT is currently being tested in home and education settings, making it cheaper and easier to deliver.<sup>64</sup> Despite this, families face a postcode lottery in their access to PACT. This is an unjustified source of health inequality.

### Autistica has:


- Published an evidence summary on parent-led video feedback therapies, recommending that “all local areas should have professionals accredited to deliver PACT”.<sup>40</sup>
- Working knowledge of many of the most promising interventions currently being developed to support autistic people and families.

### The government needs to:

- 7.1 Establish a central fund to launch new therapies into practice within the NHS, social care, and education systems.** The fund should cover the training costs for professionals to learn new manualised therapies and enable services/commissioners to backfill roles for a short time while therapists become practised in the new intervention. The Fund should start by rolling out the PACT therapy nationally and expect to support post-diagnostic empowerment programmes soon. Autistica can provide costings for this.
- 7.2 Apportion a small fund to digitalise training programmes for key therapies.** For example, PACT training could be fully digitalised for a small investment of approximately £150-200k. This would reduce the cost of training each professional by up to 50% and make it possible to develop a virtual professional network, to provide ongoing supervision and advice to newly accredited therapists.
- 7.3 Fund an expert group of intervention scientists, autistic people, families, and research bodies to shortlist the most promising interventions for the launcher.** Interventions should be prioritised based on their fit to community priorities, the quality of evidence for their acceptability, feasibility, and efficacy, how likely they are to improve existing practice, and how ready they are for roll-out.

# Trials Fund

## Trial infrastructure to accelerate the development of new interventions and supports

 "Epilepsy is the leading cause of early death for autistic people with a learning disability... Between 15% and 40% of people with epilepsies are autistic... 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"<sup>65</sup>

**Why is this important?** We've guessed away people's lives for far too long. Autistic people deserve supports that are carefully designed and rigorously tested to meet their needs. Services cannot close the inequalities between autistic and non-autistic people without high-quality intervention studies to find ways of improving outcomes.

 "Every year the state spends over £5.2 billion on social care for autistic people and people with learning disabilities with inadequate evidence... An Autistica-funded scoping review struggled to find any reliable studies that tested the effectiveness of social care interventions or service models for autistic people"<sup>66</sup>

**What is the current situation?** There are no well-evidenced interventions for many of the issues that have the biggest impact on autistic people's lives. Many existing autism intervention studies were poorly designed and at high risk of bias.<sup>67,68</sup> Although research funders have increased the number of intervention studies with autistic people in recent years,<sup>69</sup> investment is still orders of magnitude below what is needed to achieve the Government's Autism Strategy and NHS Long Term Plan commitments.


Autism research in the UK lacks central coordination. There remains a disconnect between the interventions that get studied and those that autistic people and families want. Scientists receive no clarity on interventions that are most needed by front line services. Projects vital to achieving national policy commitments fail to secure funding because they compete with proposals from fields with stronger scientific infrastructure.

The government's new Autism Strategy for England commits to developing an Autism Research Action Plan. That Action Plan should provide the funding and infrastructure to accelerate intervention studies for essential unmet support needs. Autism is a condition commonly diagnosed and spanning an entire lifespan. Between the National Health Service and the UK's high-quality research base, we could build the infrastructure to meet the needs of autistic people. Examples that the Autism Research Action Plan could draw off include:

- *The RECOVERY Trial* – A national platform trial created rapidly by public research funders in the UK to consolidate and streamline research into treatments for COVID-19. The RECOVERY Trial is widely considered to be an enormous success, finding the world's first effective COVID-19 treatment and saving millions of lives.<sup>70,71,72</sup> The field of autism intervention studies shares many of the inefficiencies and quality issues that the scale and simplicity of the RECOVERY trial successfully overcame. Applying a similar model for autism intervention research could be a game-changer.
- *The Autism CRC* – An Australian cooperative research centre focused on autism, established to provide "national capacity to develop and deliver evidence-based outcomes" through "collaboration with the autism community, research organisations, industry and government."<sup>73</sup>
- *The IACC* – A national committee sponsored by the United States Department of Health & Human Services that monitors and directs autism research investments from research funders.<sup>74</sup>

### Autistica has:

- Led a large priority setting exercise to identify the autism community's top priorities for research and maximise the impact of scientific investments.<sup>52,75</sup>
- Run collaborative summits with autistic people, family members, professionals, and scientists to identify the top research priorities on various topics, including physical health & wellbeing,<sup>76</sup> social care,<sup>77</sup> epilepsy,<sup>78</sup> artificial intelligence<sup>79</sup> and mental health.<sup>80</sup>
- Built critical scientific infrastructure, like the Autistica Network,<sup>81</sup> Insight Group,<sup>82</sup> and Research Passports<sup>83</sup> to make it easier for researchers to co-produce, recruit for, and run higher-quality intervention studies with autistic people.
- Funded a range of studies, designing and testing interventions for autistic people's priorities.<sup>84</sup>
- Reviewed the imbalance in funding for different types of autism research within the UK.<sup>69</sup>

 "The Autistica Plan is grounded in the most up-to-date evidence and, importantly, also points the way forward for how strategic funding of research in the future can and should be used to build on this early work."

*Professor Jonathan Green, University of Manchester, Manchester University NHS Foundation Trust*

### Autistica will:

- 8.1 **Help identify the most pressing unmet support needs among autistic people to prioritise for intervention R&D.** Anonymised data from the Personal Support Profiles and systematic reviews of interventions for autistic people could help achieve this. Unfortunately, Autistica doesn't currently have the resources to fund the design and full trialling of interventions from the outset to completion. However, we will help the government and public funders where we can.

### The government needs to:

- 8.2 **Work with autism research funders to create a single national strategic initiative that directs investment in intervention studies for autistic people for 5-10 years.** The Autism Research Action Plan should focus on the operation and governance for this initiative.
- 8.3 **Establish an Autism Supports Fund at the next Spending Review** to fuel the co-design and testing of interventions to improve autistic people's outcomes.



## Everyday Tips Network

### *Crowd-sourced, quality-checked practical tips from the autism community*

**Why is this important?** Autistic people and families can face lots of everyday challenges, from finding a stim tool to use at work, to figuring out how to help their child try new foods or develop healthy sleep routines. Rather than systematically collecting and sharing learnings from other autistic people and families, we leave everyone to run the gauntlet of trial and error themselves.

**What is the current situation?** Some practical tips are incorporated in post-diagnostic psychoeducation programmes, but the amount of content they can deliver in these sessions must be carefully managed. Autistic people and families will still be discovering practical difficulties they need ideas for after their time in a post-diagnostic information and empowerment programme has ended. Many personal experiences and tips are available online, for example, from charities or from autistic- or parent-led groups. However, that information is dispersed widely and rarely moderated. This can force newly diagnosed autistic people and parents to hunt for ideas across the web, all while trying to differentiate helpful tips from misleading or harmful information.

#### Autistica has already:

- A track record of creating citizen science initiatives to empower autistic people and families to share their experiences of different sensory environments.<sup>85</sup>
- A wide network of autistic people and family members who are keen to take part in research.

#### Autistica will:

- 9.1 **Create a citizen science platform (or 'Tips Network') to crowd-source descriptions and practical tips for everyday challenges.** We will then work with autistic people, parents/ carers, clinicians, professionals, and autism charities to curate those insights into trusted content that can be used across different resources, including the Newly-Diagnosed App.





# Projects to enable breakthroughs

## Part III: Lifelong Support

Abandoning autistic people and families after diagnosis and expecting them to rely on mainstream services is not working. Too often, autistic people end up in A&E, inpatient mental health services, residential care, the criminal justice system, or on the streets before public services intervene. When someone begins to experience difficulties, it is hard for them to navigate services and get the support they need.

**Feasibility is critical.** There is currently no long-term support system for most autistic people, so we should focus on developing a “minimal viable product” that can be added to iteratively.

A Stepped Care System could meet this brief. In stepped care, autistic people would mostly manage independently or with support from family/carers. However, rather than being abandoned by public services, autistic people will have an ongoing link to a specialist service they can access support from if their needs begin to escalate, as well as constant access to a suite of supports that they and their family can use by themselves. A stepped care system is held together by a shared record system, which enables an autistic person to move between ‘stepped up’ and ‘stepped down’ support as needed. ‘Step-up’ services may have a role in advising services that provide long-term care to autistic people with high support needs.

# Autism Step-Up Services

## Specialist services to be the cornerstone of a long-term support system

**Why is this important?** Although improving the support available to autistic people around and after diagnosis should prevent many needs from escalating, there will be times where people need a bit more help. Expecting autistic people to rely on mainstream or informal support during those times is not working. Too often, autistic people end up in A&E, inpatient mental health services, residential care, the criminal justice system, or the streets before public services intervene. When someone begins to experience difficulties, it is hard for them to navigate services and get the support they need.


**What is the current situation?** Most autistic people can only access specialist support after they have reached a crisis point, if at all. This is morally, politically and financially unsustainable. It is extremely difficult and expensive to help an autistic person who has reached a crisis, developed a life-threatening eating disorder, is homeless, or has become so distressed that their behaviour is dangerous to themselves or others. Public services trying to firefight these issues generate a predictable series of abuses, failures, and scandals. High profile public programmes like Transforming Care are undermined by the lack of services to prevent autistic people from reaching a crisis and being considered for inpatient admission.

A Step-Up Service should exist to meet this need. They should be a focal point of expertise in autistic people's health which an autistic person or their carer could request support, ideally through a digital case management system. There are various functions that Step-Up Services could potentially provide:

- Supporting self-management – Supporting people to manage their needs as independently as possible has been a major success for other groups (like people with asthma)<sup>86</sup> and should be the core function of Step-Up Services for autistic people. Some existing Specialist Autism Teams have used drop-in service models, support groups, or helpline services to offer advice to autistic people or direct them to sources of support. Other services host peer-led support groups and other low-intensity supports, like social activities, to help autistic people.<sup>2</sup>

 **“Regularly supported self-management reduces the use of healthcare resources and improves quality of life across all levels of asthma severity.”<sup>86</sup>**

- Managing health or social care needs – Step-Up Services would be well placed to deliver interventions specific to autism pathways: like running post-diagnostic information and empowerment programmes or building Personal Support Profiles. Depending on their skills-mix, Step-Up Services could also take the lead in providing other specialist interventions – like mental health, occupational, or speech and language therapies – for autistic people with co-occurring support needs.<sup>2</sup>

 **“It may be cost-effective for SATs to deliver one-to-one mental health interventions in service... Some SATs operated on a model whereby non-complex mental health problems (or those not directly arising from autism diagnosis) were managed by referring on to generic community mental health services. However, such referrals (i.e. handover, assessment and intervention) need to be supported by the SAT...”<sup>2</sup>**

- Advising other local services – If an autistic person is at high risk from a health or care crisis, services with expertise in the specifics of their problem will be better suited to helping them. However, as the local hub of expertise on autistic people's health, Step-Up Services may still have a role to play. They could advise mainstream or specialised services that regularly see autistic people on adaptations they should be prepared to make. They may provide supported

referrals to specialist services if they identify an acute health issue, or they could help autistic people recover after receiving crisis care. If there are autistic people being in local residential or supported living care, Step-Up Services could potentially consult on their health and wellbeing.

- Promoting good health – Other NHS services will deliver broad health promotion and protection activities, like annual health checks, vaccination drives, and health screening programmes, to autistic people. However, Step-Up services could still inform autistic people about these initiatives and advise local services on reasonable adjustments they should consider when delivering them. For example, if a Step-Up Service includes primary care expertise, they could help encourage and advise local GP practices on offering the upcoming health checks to autistic people.

### Autistica will:

- 10.1 **Partner on a proposal to trial the feasibility and cost-effectiveness of a Step-Up Service.**

### Public research funders need to:

- 10.2 **Fund trials to establish the feasibility, acceptability, and cost-effectiveness of different Step-Up Service models.** Trials could compare different models of Step-Up Support to determine which are most effective at supporting self-management, particularly drop-in and open discharge models.<sup>2</sup>

### The NHS and social care services must:

- 10.3 **Publish a plan for developing the workforce needed to deliver Step-Up Service models that are found to be feasible.**



**“I am so excited about this new, co-produced Autistica Support Plan. As a researcher and parent of an autistic young person, I wholeheartedly agree with the priorities in this plan, and I have a huge amount of faith in Autistica to spearhead this work. I hope that the Government, health, social care, education and funding agencies will all get on board with this carefully-planned and inequality-busting process.”**

*Professor Sue Fletcher-Watson, University of Edinburgh*



# Self-Directed Supports Library

## Therapeutic tools that autistic people/families can use themselves without public services

**Why is this important?** Autistic people should be supported to live the most autonomous lives possible. Realistically, most autistic people will not (and should not) be constantly receiving support from specialist services. Instead, most autistic people and families will need to manage by themselves most of the time. Rather than completely abandoning autistic people and families, we should arm them with well-evidenced supports they can use by themselves (or with a friend/carer) to achieve their goals and lead fulfilling lives.

In a stepped care system, self- or community-delivered support would be complemented by the digital case management system, which provides autistic people with an ongoing link to specialist support.

**“The findings make a strong case [for] interventions and practice that nurture self-management with respect to mental health, managing day-to-day life and strengthening social networks.”<sup>2</sup>**

**What is the current situation?** Currently, most autistic people and families are left to fend for themselves. Many individuals, charities, and local groups have created resources that can be used without direct support from health and care professionals. However, there is no central repository of these supports, and very few are tested to ensure they are acceptable, effective, and safe.

### Autistica has:

- Self-guided anxiety therapy – Co-developed and tested Molehill Mountain, an App delivered toolkit of adapted therapies trialled with young autistic people by Kings College London.<sup>43</sup> A pilot trial of other online self-guided CBT and mindfulness tools recently published promising results.<sup>87</sup>
- Environment navigation – Funded the development of a citizen science platform with the Alan Turing Institute, where people can share insights about the accessibility of different environments, along with practical coping strategies.<sup>88</sup>
- Communication aids – Funded the HoPS study to pilot an adaptation of the Picture Exchange Communication System (PECS) communication system for children and parents for use at home.<sup>89</sup>
- Social prescribing – Funded a Study Group of autistic people, clinicians and researchers to publish an initial framework for considering social prescribing for autistic people.<sup>90</sup>
- Peer support – Identified autistic-led peer mentoring and peer-supporter models as a community research priority.<sup>77</sup>

### Autistica will:

- 11.1 Co-produce a list of support needs that would be strong targets for self-delivered interventions.** The Tips Network and Personal Support Profiles could produce insights on which we would consult autistic people, families, clinicians, and researchers.
- 11.2 Compile and curate a library of well-evidenced self-directed supports.** Ideally, this support library would later be hosted within the co-owned health record system.

### Autistica & NIHR’s Research for Social Care Programme plans to:

- 11.3 Fund the development & evaluation of supports that can be delivered by autistic people, carers, community groups or local care services.<sup>91</sup>**





## Co-Owned Record System

### Shared record system to facilitate stepped care

**Why is this important?** Seamless case management is the core of the stepped care system. Autistic people, carers and healthcare professionals need access to consistent records to manage needs and coordinate support. Digitalising case management would improve connectivity and reduce the number of new staff needed to operate it.

**What is a digital case management system?** Theoretically, an autistic person (or carer) could be given a login to an app or website that enables them to:

- Access their health record, Health Checks, and their Personal Support Profile,
- Find or request additional support from a Step-Up Service,
- Access a curated Library of Self-Directed Supports, and
- See and request changes to the Reasonable Adjustment Flag that is visible across their health record.

This could be achieved through a shared or co-owned record system, with a 'front end' that autistic people and families can use and a 'back end' that can integrate with NHS records (and potentially social care and education records). A professional would need to work within the digital system to manage requests for support or proactively offer it if concerned by any new information. While parents/carers would initially hold the 'front end' login to their child's health records, autistic adults would take over access as they get older.

 **“Professionals expressed dissatisfaction with post-diagnostic provision, especially onward and long-term support”<sup>3</sup>**

**What is the current situation?** There is no central system that connects autistic people and carers to specialist support. A few Specialist Autism Teams “keep autistic people on their books” and continue to support them periodically, but this is managed manually and rarely available.

However, digital resources are being used to manage care in other parts of the health system, for example:

- EMPOWER App – A smartphone App that is being trialled to help people with schizophrenia monitor for warning signs of relapses in their mental health as part of a Stepped Care pathway.<sup>92</sup>
- CFHealthHub – A digital self-care platform for people with Cystic Fibrosis and clinical teams that was recently evaluated in a Randomised Controlled Trial across 19 CF centres.<sup>93</sup>
- Parkinson's Connect – A new digital service being designed by Parkinson's UK to provide people with Parkinson's with self-management tools and provide access to specialist NHS services.<sup>94</sup>
- SOLID project – An NHSX-funded project that is scoping digital innovations, like the use of shared digital records, with NHS England's Autism and Learning Disability Programme.

#### Autistica will:

- 12.1 **Support a project to scope the functionality and operational requirements of a digital case management system for autistic people.**

#### The government and public research funders need to:

- 12.2 **Fund the design and evaluation of a digital case management system** to support long term stepped care for autistic people.

## Health Checks for Autistic People

### Evidenced checks to help autistic people manage their health needs

**Why is this important?** Some autistic people and families may be unlikely to seek support from mainstream services, specialist care or general screening programmes when they need to. Annual, tailored health checks could offer parity of healthcare to autistic people and become a vital component of effective long term stepped care.

**What is the current situation?** Autistica's health check has now been co-produced with autistic adults, family members and GPs by a research consortium led by Newcastle University. The health checks are currently being trialled in NHS services with funding from NHS England and Autistica.

The checks' bio-psycho-social approach to autistic people's health and wellbeing should complement the Personal Support Profiles. If the trial is successful, the health checks could support autistic adults/carers to self-manage chronic health issues, and help trigger stepped up support when needed.

#### Autistica has:

- Funded the development and testing of a co-produced health check for autistic adults, with support from the Peter Sowerby Foundation.<sup>95</sup>
- Partnered with NHS England to expand the pilot study to a full trial of the health checks.
- Secured a commitment in the NHS Long Term Plan to roll out the health checks should the trial prove successful.<sup>19</sup>
- Funded a behavioural insights project to identify barriers to health check uptake among GPs.

#### Autistica will:

- 13.1 **Develop a strategic plan to ensure that every autistic adult is offered a tailored health check.**

#### The Government and NHS need to:

- 13.2 **Deliver the NHS Long Term Plan commitment and commission health checks for autistic people** if the randomised control trial indicates they are likely to be effective.





# References

1. Crane L, et al. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *J Autism Dev Disord* 48, 3761–3772. [doi.org/10.1007/s10803-018-3639-1](https://doi.org/10.1007/s10803-018-3639-1)
2. Beresford B, et al. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Serv Deliv Res*. 8(48) [journalslibrary.nihr.ac.uk/hsdr/hsdr08480](https://journalslibrary.nihr.ac.uk/hsdr/hsdr08480)
3. Rogers CL, et al. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism*. 20(7):820-31. [pubmed.ncbi.nlm.nih.gov/26681687/](https://pubmed.ncbi.nlm.nih.gov/26681687/)
4. Crane L, et al. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*. 20(2):153-62. [pubmed.ncbi.nlm.nih.gov/25810370/](https://pubmed.ncbi.nlm.nih.gov/25810370/)
5. Potter, CA. (2017). "I received a leaflet and that is all": Father experiences of a diagnosis of autism. *Br J Learn Disabil*. 45: 95– 105. [doi.org/10.1111/bld.12179](https://doi.org/10.1111/bld.12179)
6. BBC News (2021). Autism and anxiety: One man 'failed by the system'. [bbc.co.uk/news/av/uk-58334061](https://www.bbc.co.uk/news/av/uk-58334061)
7. NHS Digital (2021). Reports from Assuring Transformation Collection. <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/assuring-transformation/reports-from-assuring-transformation-collection>
8. ONS (2021). Outcomes for disabled people in the UK: 2020. [ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020#employment](https://ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020#employment)
9. Autistica (2021). Autistic people still face highest rates of unemployment of all disabled groups. [autistica.org.uk/news/autistic-people-highest-unemployment-rates](https://autistica.org.uk/news/autistic-people-highest-unemployment-rates)
10. Autistica (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in autism. [autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf](https://autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf)
11. Autistica (2019). Building Happier Healthier Longer Lives: Briefings to improve autism policy and research. [autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](https://autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf)
12. Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. *Br J Psychiatry*, 208(3):232-8 [pubmed.ncbi.nlm.nih.gov/26541693/](https://pubmed.ncbi.nlm.nih.gov/26541693/)
13. 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://niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2021/finance/0821.pdf)
14. Buescher AV, et al. (2014) Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr*. 168(8):721-8. [pubmed.ncbi.nlm.nih.gov/24911948/](https://pubmed.ncbi.nlm.nih.gov/24911948/)
15. DHSC (2015). 2010 to 2015 government policy: cancer research and treatment [Policy Paper]. [gov.uk/government/publications/2010-to-2015-government-policy-cancer-research-and-treatment/2010-to-2015-government-policy-cancer-research-and-treatment](https://www.gov.uk/government/publications/2010-to-2015-government-policy-cancer-research-and-treatment/2010-to-2015-government-policy-cancer-research-and-treatment)
16. NHS England (2019). The Long Term Plan is a game changer. [england.nhs.uk/blog/the-long-term-plan-is-a-game-changer/](https://www.england.nhs.uk/blog/the-long-term-plan-is-a-game-changer/)
17. Russell G, et al. (2021). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *J Child Psychol Psychiatr*. [doi.org/10.1111/jcpp.13505](https://doi.org/10.1111/jcpp.13505)
18. Autistica analysis using data from: NHS Digital (2021). Health and Care of People with Learning Disabilities Experimental Statistics 2019 to 2020. [digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2019-to-2020](https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2019-to-2020)
19. NHS England (2019). The NHS Long Term Plan. [longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf)
20. DHSC, DfE (2021). National strategy for autistic children, young people and adults: 2021 to 2026. [gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026](https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)
21. House of Commons (April 2021). Oral evidence: Treatment of autistic people and individuals with learning disabilities, HC 1195. [Page 15, Q131] [committees.parliament.uk/oralevidence/2102/pdf/](https://committees.parliament.uk/oralevidence/2102/pdf/)
22. Calculated using tables 3 and 4 from Buescher AV, et al. (2014) Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr*. 168(8):721-8. [pubmed.ncbi.nlm.nih.gov/24911948/](https://pubmed.ncbi.nlm.nih.gov/24911948/)
23. Motlova LB, Balon R, Beresin EV, et al. (2017). Psychoeducation as an Opportunity for Patients, Psychiatrists, and Psychiatric Educators: Why Do We Ignore It?. *Acad Psychiatry* 41, 447–451. [doi.org/10.1007/s40596-017-0728-y](https://doi.org/10.1007/s40596-017-0728-y)
24. Lavell C, et al. (2020). Chapter 3 - Psychoeducation for exposure therapy. In Peris TS, et al. *Exposure Therapy for Children with Anxiety and OCD*. Academic Press, 39-67. [doi.org/10.1016/B978-0-12-815915-6.00003-2](https://doi.org/10.1016/B978-0-12-815915-6.00003-2)
25. Wu MS, McGuire JF (2018). Chapter 2 - Psychoeducation About Tic Disorders and Treatment. In McGuire JF, et al. *The Clinician's Guide to Treatment and Management of Youth with Tourette Syndrome and Tic Disorders*, Academic Press, 21-41. [doi.org/10.1016/B978-0-12-811980-8.00002-9](https://doi.org/10.1016/B978-0-12-811980-8.00002-9)
26. Hirvikoski T, et al. (2017). Psychoeducational groups for adults with ADHD and their significant others (PEGASUS): A pragmatic multicenter and randomized controlled trial. *Eur Psychiatry*. 44:141-152. [pubmed.ncbi.nlm.nih.gov/28641216/](https://pubmed.ncbi.nlm.nih.gov/28641216/)
27. Papadopoulos C, et al. (2019). Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health. *J Autism Dev Disord*. 49(4):1665-1685. [pubmed.ncbi.nlm.nih.gov/30569408/](https://pubmed.ncbi.nlm.nih.gov/30569408/)
28. Green J, et al. (2017). REACH-ASD Trial: A Randomised Controlled Trial of Psychoeducation and Acceptance & Commitment Therapy for Parents of Children recently diagnosed with ASD. NIHR HTA Programme [webpage with trial protocol, last updated January 2021] [fundingawards.nihr.ac.uk/award/17/80/09](https://fundingawards.nihr.ac.uk/award/17/80/09)
29. Leadbitter K, et al. (2021). Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice. *Front. Psychol*. 12:635690 [frontiersin.org/articles/10.3389/fpsyg.2021.635690/full](https://frontiersin.org/articles/10.3389/fpsyg.2021.635690/full)
30. University of Edinburgh (2021). EPIC research study. <https://www.ed.ac.uk/clinical-brain-sciences/research/epic-edinburgh-psychoeducation-intervention/epic-research>
31. Lodder A, Papadopoulos C, Randhawa G (2020). SOLACE: A Psychosocial Stigma Protection Intervention to Improve the Mental Health of Parents of Autistic Children-A Feasibility Randomised Controlled Trial. *J Autism Dev Disord*. 50(12):4477-4491. [pubmed.ncbi.nlm.nih.gov/32323046/](https://pubmed.ncbi.nlm.nih.gov/32323046/)
32. Palmer M, et al. (2020). Feasibility study of the National Autistic Society EarlyBird parent support programme. *Autism*. 24(1):147-159. [pubmed.ncbi.nlm.nih.gov/31165623/](https://pubmed.ncbi.nlm.nih.gov/31165623/)
33. Pillay M, et al. (2011). Autism Spectrum Conditions--enhancing Nurture and Development (ASCEND): an evaluation of intervention support groups for parents. *Clin Child Psychol Psychiatry*. 16(1):5-20. [pubmed.ncbi.nlm.nih.gov/20223793/](https://pubmed.ncbi.nlm.nih.gov/20223793/)
34. Charman R, et al. (2021). A Novel Group Parenting Intervention for Emotional and Behavioral Difficulties in Young Autistic Children: Autism Spectrum Treatment and Resilience (ASTAR): A Randomized Controlled Trial. *J Am Acad Child Adolesc Psychiatry*. 60(11):1404-1418. [jaacp.org/article/S0890-8567\(21\)00298-7/fulltext](https://jaacp.org/article/S0890-8567(21)00298-7/fulltext)
35. Stuttard L, et al. (2014). Riding the rapids: living with autism or disability--an evaluation of a parenting support intervention for parents of disabled children. *Res Dev Disabil*. 35(10):2371-83. [pubmed.ncbi.nlm.nih.gov/24973545/](https://pubmed.ncbi.nlm.nih.gov/24973545/)
36. McKenzie R, et al. (2019). SAFE, a new therapeutic intervention for families of children with autism: study protocol for a feasibility randomised controlled trial. *BMJ Open*. 27;9(5):e025006. [pubmed.ncbi.nlm.nih.gov/31133577/](https://pubmed.ncbi.nlm.nih.gov/31133577/)
37. Gordon K, et al. (2015). A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder. *J Child Psychol Psychiatry*. 56(4):468-76. [pubmed.ncbi.nlm.nih.gov/25132516/](https://pubmed.ncbi.nlm.nih.gov/25132516/)
38. Groenendijk ER, van Heijst BFC, Geurts HM (2021). Co-designed Psychoeducation for older autistic adults: Multiple case time series. *PsyArXiv*. [Preprint] [psyarxiv.com/tuwyb/](https://psyarxiv.com/tuwyb/)
39. Autistica (2020). Autistica evidence resource: Supporting autistic children and young people through crisis. Available at: [autistica.org.uk/news/resources-for-professionals-supporting-autistic-people-in-crisis](https://autistica.org.uk/news/resources-for-professionals-supporting-autistic-people-in-crisis)
40. Autistica (2018). Autistica Evidence Summary on Parent-led video feedback therapy: communication interventions for young autistic children. [autistica.org.uk/downloads/files/Autistica-evidence-summary-Parent-led-video-feedback-therapy-4.pdf](https://autistica.org.uk/downloads/files/Autistica-evidence-summary-Parent-led-video-feedback-therapy-4.pdf)
41. Abrahamson V, et al. (Not yet published, protocol published 2020). Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): which diagnostic pathways work best, for whom and in what context? Protocol for a rapid realist review. *BMJ Open*, 10(7):e037846. [pubmed.ncbi.nlm.nih.gov/32636288/](https://pubmed.ncbi.nlm.nih.gov/32636288/)
42. Leeds University (2021). Clearing House for Postgraduate Courses in Clinical Psychology > Numbers. [leeds.ac.uk/chpccp/numbers.html](https://leeds.ac.uk/chpccp/numbers.html)
43. Autistica (2020). Molehill Mountain: How does the app work? <https://www.autistica.org.uk/molehill-mountain/how-does-the-app-work>
44. Lloyd-Esenkaya V, Russell A (2021). The practice of strengths and needs assessment as part of the autism diagnostic pathway for children and adults without associated intellectual disability. [Unpublished Scoping Report commissioned by NHS England and Improvement's Autism Team]
45. Bölte S, et al. (2021). Reconciling the seemingly irreconcilable: The WHO's ICF system integrates biological and psychosocial environmental determinants of autism and ADHD: The International Classification of Functioning (ICF) allows to model opposed biomedical and neurodiverse views of autism and ADHD within one framework. *Bioessays*. 1:e2000254. [pubmed.ncbi.nlm.nih.gov/33797095/](https://pubmed.ncbi.nlm.nih.gov/33797095/)
46. Karolinska Institutet (2021). Standardizing assessment of functioning and disability in ADHD and ASD (webpage). [ki.se/en/kind/standardizing-assessment-of-functioning-and-disability-in-adhd-and-asd](https://ki.se/en/kind/standardizing-assessment-of-functioning-and-disability-in-adhd-and-asd)
47. Napoli SB, et al. (2021). Developing a Culturally Sensitive ICF-Based Tool to Describe Functioning of Children with Autism Spectrum Disorder: TEA-CIFunciona Version 1.0 Pilot Study. *Int J Environ Res Public Health*. 2;18(7):3720. [pubmed.ncbi.nlm.nih.gov/33918291/](https://pubmed.ncbi.nlm.nih.gov/33918291/)
48. Courts and Tribunals Judiciary (2020). Sophie Bennett: Prevention of Future Deaths report. [judiciary.uk/publications/sophie-bennett](https://www.judiciary.uk/publications/sophie-bennett)
49. Autism CRC (2021). Interventions for children on the autism spectrum: A synthesis of research evidence. Available: [autismcrc.com.au/interventions-evidence](https://autismcrc.com.au/interventions-evidence)
50. French L, Kennedy EM (2018). Annual Research Review: Early intervention for infants and young children with, or at-risk of, autism spectrum disorder: a systematic review. *J Child Psychol Psychiatr*, 59: 444-456. [doi.org/10.1111/jcpp.12828](https://doi.org/10.1111/jcpp.12828)

51. Bölte S, et al. (2019). The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus International Classification of Functioning, Disability and Health core sets. *Autism*. 23(2):449-467. [pubmed.ncbi.nlm.nih.gov/29378422/](https://pubmed.ncbi.nlm.nih.gov/29378422/)
52. Autistica, James Lind Alliance (2016). Your questions: shaping future autism research. Available: [autistica.org.uk/our-research/your-research-priorities](https://autistica.org.uk/our-research/your-research-priorities)
53. Green J, et al. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet* 375(9732):2152-60 [pubmed.ncbi.nlm.nih.gov/20494434/](https://pubmed.ncbi.nlm.nih.gov/20494434/)
54. Pickes A, et al. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *Lancet* 388(10059):2501-2509. [doi.org/10.1016/S0140-6736\(16\)31229-6](https://doi.org/10.1016/S0140-6736(16)31229-6)
55. NICE (2013). NICE Clinical Guideline 128: Autism spectrum disorder in under 19s: recognition, referral and diagnosis. [nice.org.uk/guidance/cg170/chapter/Key-priorities-for-implementation#psychosocial-interventions](https://nice.org.uk/guidance/cg170/chapter/Key-priorities-for-implementation#psychosocial-interventions)
56. NIHR (2017). Alert: Parent-focused therapy has some long-term benefits for children with autism. [doi.org/10.3310/signal-000381](https://doi.org/10.3310/signal-000381)
57. Kasari C, et al. (2014). Communication interventions for minimally verbal children with autism: a sequential multiple assignment randomized trial. *J Am Acad Child Adolesc Psychiatry*. 53(6):635-46. [pubmed.ncbi.nlm.nih.gov/24839882/](https://pubmed.ncbi.nlm.nih.gov/24839882/)
58. Whitehouse AJO, et al. (2019). Pre-emptive intervention versus treatment as usual for infants showing early behavioural risk signs of autism spectrum disorder: a single-blind, randomised controlled trial. *Lancet Child Adolesc Health*. 3(9):605-615. [pubmed.ncbi.nlm.nih.gov/31324597/](https://pubmed.ncbi.nlm.nih.gov/31324597/)
59. Green J, et al. (2015). Parent-mediated intervention versus no intervention for infants at high risk of autism: a parallel, single-blind, randomised trial. *Lancet Psychiatry*. 2(2):133-40. [pubmed.ncbi.nlm.nih.gov/26359749/](https://pubmed.ncbi.nlm.nih.gov/26359749/)
60. Green J, et al. (2017). Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *J Child Psychol Psychiatry*. 58(12):1330-1340. [pubmed.ncbi.nlm.nih.gov/28393350/](https://pubmed.ncbi.nlm.nih.gov/28393350/)
61. Rahman A, et al. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. *Lancet Psychiatry*. 3(2):128-36. [pubmed.ncbi.nlm.nih.gov/26704571/](https://pubmed.ncbi.nlm.nih.gov/26704571/)
62. Whitehouse AJO, et al. (2021). Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis. *JAMA Pediatr*. [online]. [jamanetwork.com/journals/jamapediatrics/fullarticle/2784066](https://jamanetwork.com/journals/jamapediatrics/fullarticle/2784066)
63. IMPACT CIC (2021). Pact Training [website]: [pacttraining.co.uk/](https://pacttraining.co.uk/)
64. Green J, et al. (2018). Paediatric Autism Communication Therapy-Generalised (PACT-G) against treatment as usual for reducing symptom severity in young children with autism spectrum disorder: study protocol for a randomised controlled trial. *Trials* 19, 514 [doi.org/10.1186/s13063-018-2881-3](https://doi.org/10.1186/s13063-018-2881-3)
65. Autistica (2019). Autistica Briefing on Epilepsies. Available: [autistica.org.uk/our-research/policy-recommendations-briefings](https://autistica.org.uk/our-research/policy-recommendations-briefings)
66. Autistica (2020). Autistica Briefing on Social Care: We cannot accept another Whorlton Hall. Available: [autistica.org.uk/our-research/policy-recommendations-briefings](https://autistica.org.uk/our-research/policy-recommendations-briefings)
67. Bottema-Beutel K, et al. (2020). Research Review: Conflicts of Interest (COIs) in autism early intervention research – a meta-analysis of COI influences on intervention effects. *J. Child Psychol. Psychiatr.* 62(1):5-15. [onlinelibrary.wiley.com/doi/epdf/10.1111/jcpp.13249](https://onlinelibrary.wiley.com/doi/epdf/10.1111/jcpp.13249)
68. Dawson M, Fletcher-Watson S (2021). When autism researchers disregard harms: A commentary. *Autism*. 22:13623613211031403. [journals.sagepub.com/doi/pdf/10.1177/13623613211031403](https://journals.sagepub.com/doi/pdf/10.1177/13623613211031403)
69. Autistica (2019). A review of the autism research funding landscape in the United Kingdom. Available: [autistica.org.uk/our-research/uk-research-review](https://autistica.org.uk/our-research/uk-research-review)
70. UKRI (2021). The RECOVERY trial. [webpage] [ukri.org/our-work/tackling-the-impact-of-covid-19/vaccines-and-treatments/recovery-trial-identifies-covid-19-treatments/](https://ukri.org/our-work/tackling-the-impact-of-covid-19/vaccines-and-treatments/recovery-trial-identifies-covid-19-treatments/)
71. Mullard A (2021). RECOVERY 1 year on: a rare success in the COVID-19 clinical trial landscape. *Nature Reviews Drug Discovery* 20, 336-337. <https://doi.org/10.1038/d41573-021-00068-w>
72. Kupferschmidt K (2020). One U.K. trial is transforming COVID-19 treatment. Why haven't others delivered more results? *Science Magazine*. [sciencemag.org/news/2020/07/one-uk-trial-transforming-covid-19-treatment-why-haven-t-others-delivered-more-results](https://sciencemag.org/news/2020/07/one-uk-trial-transforming-covid-19-treatment-why-haven-t-others-delivered-more-results)
73. Autism CRC (2021). Autism CRC: About us [webpage]. [autismcrc.com.au/about-us](https://autismcrc.com.au/about-us)
74. HSS (2021). Interagency Autism Coordinating Committee [website] [iacc.hhs.gov/](https://iacc.hhs.gov/)
75. NIHR (2019). Case study: Collaborating to maximise the impact of autism research. [nihr.ac.uk/documents/case-studies/collaborating-to-maximise-the-impact-of-autism-research/23230](https://nihr.ac.uk/documents/case-studies/collaborating-to-maximise-the-impact-of-autism-research/23230)
76. Autistica (2017). Autistica Health and Well-being Summit Report: How can we improve autistic adults' physical health and well-being? [autistica.org.uk/our-research/collaborative-workshops-or-summits/health-and-wellbeing-summit](https://autistica.org.uk/our-research/collaborative-workshops-or-summits/health-and-wellbeing-summit)
77. Autistica (2019). Autistica Social Care Summit Report: How can research improve social care for autistic adults? [autistica.org.uk/our-research/collaborative-workshops-or-summits/social-care-summit](https://autistica.org.uk/our-research/collaborative-workshops-or-summits/social-care-summit)
78. Autistica (2018). Autistica Epilepsy Summit Report: How can research into autism and epilepsy save lives? [autistica.org.uk/our-research/collaborative-workshops-or-summits/epilepsy-summit](https://autistica.org.uk/our-research/collaborative-workshops-or-summits/epilepsy-summit)
79. Autistica (2019). Autistica AI Summit Report: How can artificial intelligence support early intervention? [autistica.org.uk/our-research/collaborative-workshops-or-summits/ai-summit-report](https://autistica.org.uk/our-research/collaborative-workshops-or-summits/ai-summit-report)
80. Autistica (2018). National research funders prioritise mental health of autistic people. [autistica.org.uk/news/5-ways-the-government-can-transform-mental-health-in-autism](https://autistica.org.uk/news/5-ways-the-government-can-transform-mental-health-in-autism)
81. Autistica (2021). Autistica Network for researchers. [autistica.org.uk/our-research/network-researchers](https://autistica.org.uk/our-research/network-researchers)
82. Autistica (2021). Get insights on your study. [autistica.org.uk/our-research/get-insights-on-your-study-1](https://autistica.org.uk/our-research/get-insights-on-your-study-1)
83. Autistica (2021). Improving research experiences through an autistic passport. [autistica.org.uk/our-research/research-projects/improving-research-experiences-through-an-autistic-passport](https://autistica.org.uk/our-research/research-projects/improving-research-experiences-through-an-autistic-passport)
84. Autistica (2021). Our current research projects. [autistica.org.uk/our-research/research-projects](https://autistica.org.uk/our-research/research-projects)
85. Autistica, Alan Turing Institute (2018). Creating better environments: Using citizen science to help autistic people navigate the world. [autistica.org.uk/our-research/research-projects/creating-better-environments](https://autistica.org.uk/our-research/research-projects/creating-better-environments)
86. Hodkinson A, et al. (2020). Self-management interventions to reduce healthcare use and improve quality of life among patients with asthma: systematic review and network meta-analysis *BMJ*. 370:m2521 [bmj.com/content/370/bmj.m2521](https://bmj.com/content/370/bmj.m2521)
87. Gaigg SB, et al. (2020). Self-guided mindfulness and cognitive behavioural practices reduce anxiety in autistic adults: A pilot 8-month waitlist-controlled trial of widely available online tools. *Autism*.24(4):867-883. [pubmed.ncbi.nlm.nih.gov/32267168/](https://pubmed.ncbi.nlm.nih.gov/32267168/)
88. Autistica (2018). Creating better environments: Using citizen science to help autistic people navigate the world [autistica.org.uk/our-research/research-projects/creating-better-environments](https://autistica.org.uk/our-research/research-projects/creating-better-environments)
89. Autistica (2019). Home-based PECS Study (HoPS) to help with communication skills: A pilot evaluation of a home-based Picture Exchange Communication Schedule (PECS) intervention for young non- or minimally-verbal children with autism. [autistica.org.uk/our-research/research-projects/pecs-at-home](https://autistica.org.uk/our-research/research-projects/pecs-at-home)
90. Charlton RA, et al. (2021). Social prescribing for autistic people: A framework for service provision [version 2; peer review: 2 approved]. *AMRC Open Res* 2021, 2:19 [doi.org/10.12688/amrcopenres.12901.2](https://doi.org/10.12688/amrcopenres.12901.2)
91. Autistica (2021). Autistica partner with NIHR to fund breakthroughs in social care for autistic adults. [autistica.org.uk/news/working-with-nihr-autism-social-care](https://autistica.org.uk/news/working-with-nihr-autism-social-care)
92. Gumley A, et al. (2020). Early Signs Monitoring to Prevent Relapse in Psychosis and Promote Well-Being, Engagement, and Recovery: Protocol for a Feasibility Cluster Randomized Controlled Trial Harnessing Mobile Phone Technology Blended With Peer Support. *JMIR Res Protoc*. 9(1):e15058. [pubmed.ncbi.nlm.nih.gov/31917372/](https://pubmed.ncbi.nlm.nih.gov/31917372/)
93. Hinds D, et al. (2020). NIHR Funding Awards: Development and evaluation of an intervention to support Adherence to treatment in adults with Cystic Fibrosis (ACTiF). [dev.fundingawards.nihr.ac.uk/award/RP-PG-1212-20015](https://dev.fundingawards.nihr.ac.uk/award/RP-PG-1212-20015)
94. Third Sector Awards (2021). Parkinson's Connect. [thirdsectorawards.com/finalists/parkinson-s-connect](https://thirdsectorawards.com/finalists/parkinson-s-connect)
95. Autistica (2018). Design and initial evaluation of an autism-specific health check for use with autistic adults in NHS Primary Care. [autistica.org.uk/our-research/research-projects/health-checks](https://autistica.org.uk/our-research/research-projects/health-checks)



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