

# Autistica Action Briefing: Adult Mental Health

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

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

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

## What we know

"The main problem with mental health services is that no one seems to want the responsibility of putting him on their books... He keeps getting passed around departments" <sup>1</sup>

- **Almost 8 in 10 autistic adults experience a mental health problem.**<sup>2</sup> Autism is not a mental health condition itself, but mental health problems are one of the most common and serious challenges experienced by people across the spectrum.
- **Up to 10% of adults in inpatient mental health settings are autistic,**<sup>3</sup> even though only 1% of the population is on the spectrum.<sup>4</sup>
- **Autistic people are often unable to access community mental health support.**<sup>1,5,6,7</sup> Autistic people report being "punted" between different settings; often from mental health services that are not confident in "dealing with autism" to learning disability services which can be poorly integrated with mental health services.<sup>1,5,7,8</sup> This is a particular issue for adults without a learning disability, who can rarely access timely specialist mental health support, resulting in problems escalating until emergency or inpatient care is required.<sup>5,9,10,11</sup>
- **Mental health treatment may need to be adapted for autistic people.** Healthcare professionals can lack experience in the nuances of autistic people's mental health and confidence in identifying when someone's autistic traits are or are not a significant factor.<sup>5,12,13</sup> There is a developing body of evidence around adapting typical therapies such as CBT but significantly more work is needed.<sup>12,14,15,16,17</sup>
- **Mental health problems are often misdiagnosed amongst autistic adults.** Autistic people are more likely to be given a sequence of diagnoses for their mental health problems and to disagree with the diagnosis they receive.<sup>1,2,5,13</sup> The lack of validated assessment tools, high rates of overlapping and co-occurring conditions, and potential for miscommunication between clinicians and autistic people can all make diagnosing mental health problems more difficult.<sup>13</sup>

## What we need to find out

"I have anxiety and depression, but it's taken several visits to the GP to discover this" <sup>1</sup>

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

- What are the environmental and biological causes of mental health problems in autistic people? How do causes such as trauma vary for autistic people compared to non-autistic people?
- Do presentations of common mental health conditions in autistic people vary from their presentations in non-autistic people? If so, do GPs and other health professionals identify those different presentations and adjust their assessment and treatment appropriately?
- What makes a peer support programme personalised and effective for managing or improving mental health in autistic people?<sup>23</sup>
- How can talking therapies be adapted to meet the needs of autistic people?

- How can different forms of low-level support minimise the risk of mental health problems and the need for more intensive support?
- How can health professionals distinguish between physical and mental health difficulties underlying distress in autistic adults who speak few or no words?
- Are medications effective in treating mental health conditions in autistic adults? Are autistic people at risk of a different profile of side-effects? Can we determine how different medications are likely to affect different autistic people in order to better target medication?

## What we should do now

“Was asked to take part in a group, found the group too big, was told I chose not to take part and was left on my own to struggle by myself”<sup>6</sup>

- We know a lot more about mental health and autism now than we did when the Autism Act (2009)<sup>24</sup> or Think Autism Strategy (2014)<sup>25</sup> were published but mental health remains a top concern across the autistic community.<sup>2,6,22</sup>

**The Department of Health and Social Care should ensure that supporting autistic people with mental health problems remains a “priority challenge for action”<sup>26</sup> as part of the future strategy.<sup>27</sup>**

- NHS England is developing a new “*framework for adult community mental health services that will encompass the needs of people with a range of diagnoses*”.<sup>28,29</sup> The Minister for Care has indicated that this framework will include mental health support for autistic adults.<sup>30</sup>

**NHS England should ensure that the development of this framework is based on the latest evidence, that mechanisms for data collection and evaluation are in place, and that autistic people and their families are involved to ensure that the framework reflects their needs and experiences.<sup>5</sup>**

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

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

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

**Health Education England, NHS England and the Royal Colleges should ensure that there are sufficient health professionals in each area with the specialist knowledge required to meet the needs of their local communities.**

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