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## Autistic people’s mental health is worsening. We need new ways of delivering services.

Before the pandemic, autistic and other neurodivergent people faced higher rates of mental health difficulties and a lack of access to support. These inequalities are widening and will continue to do so as restrictions become more complex and changeable. A shift towards remote healthcare may be beneficial to some and completely inaccessible for others; we need to know more about how to provide digital mental health support effectively. As society opens up, it is essential we tackle the mental health crisis facing neurodivergent people, learn from positive experiences of lockdown, and build a world where those who are different can truly thrive.

### Where we are now

**The pandemic is widening the mental health inequalities facing autistic and other neurodivergent people.** Mental health difficulties, experienced by 8 in 10 autistic people, were already the norm.<sup>2,3,4</sup> Emerging research suggests that autistic people have experienced heightened anxiety and more mental health difficulties during lockdown; this increase is larger than in neurotypical people.<sup>5,6,7,8,9</sup> Data from the National Child Mortality Database suggests a possible rise in self-harm and suicidality during lockdown;<sup>10,11</sup> autistic people and those with ADHD are known to be at increased risk.<sup>12,13,14</sup>

**Neurodivergent people are facing unique challenges from lockdown measures.** Reduced access to social care<sup>15,16</sup> and other specialist input,<sup>6</sup> including charities,<sup>17</sup> have left many unable to meet their needs.<sup>5,8,18,19</sup> Social isolation is exacerbated<sup>8,20</sup> and elderly or vulnerable carers are providing care alone.<sup>6,19,21,22</sup> Uncertainty plays a major role in anxiety for autistic people,<sup>9,23,24</sup> and many report disruption to routines as their primary stressor.<sup>1,6,20,22,25,26</sup> Access to necessary food and supplies is a significant problem: “safe” products which autistic people rely on for much-needed continuity may be unavailable, compliance to social distancing rules is variable, and some for whom supermarkets are inaccessible are unable to access delivery slots as demand rises.<sup>5,8,24,25,26</sup>

**Changes to services could exacerbate existing lack of mental health support.** Even before COVID-19, neurodivergent people struggled to access mental health services.<sup>27,28,29,30</sup> The pandemic has caused major disruption and, in some cases, complete loss of services<sup>1,22,26,31</sup> just as they are needed most. Some autistic people struggle to engage with remote alternatives such as telephone and video calls.<sup>8,25,26</sup> Others find these options more accessible, creating an opportunity for long-term digital solutions – but we need to know more about which groups clinically benefit from digital delivery.<sup>32</sup>

**For some autistic people, leaving lockdown will be harder than entering lockdown.**<sup>5,8,19,22,26</sup> Pressure to attend social events, and return to stressful school or work environments with new norms, has increased anxiety for many, particularly when routines, coping strategies and usual supports remain unavailable.<sup>5,8,25,31,33</sup> For some, COVID-19 and lockdown measures have caused trauma. Almost 6 in 10 of the autistic people and families in our Insight Group members reported being unhappy with information on coming out of lockdown,<sup>31</sup> and fears over safety protocols not being followed have prevented some from taking advantage of recent relaxations.<sup>25,31</sup> Many also face increased stigma because they are unable to wear face coverings<sup>8,25,31</sup> or have tics involving coughing or spitting.<sup>21</sup>

**“Normal” wasn’t working for everyone; this is an opportunity for change.** Autistic people are more likely to report positive aspects of lockdown, such as reduced social pressures, emptier public spaces, and working or studying from home.<sup>8,25,26,31</sup> As restrictions change, some have become more anxious over a potential forced return to educational, professional and social settings that do not meet their needs.<sup>7,25,31</sup> Some autistic people and families feel that lockdown has aligned the world more closely to their existing lifestyle,<sup>19,31</sup> creating an opportunity to create a more accessible and inclusive society. It is critical that we gather data on these benefits as well as harms in order to create a world that works for every autistic person.<sup>8,19,26</sup>

Some have described a sense of relief as social demands have decreased, but there are concerns about how they will manage when the restrictions are lifted. Some have been floored by the uncertainty and change to routines. Some have been impacted by not being able to get their usual food/brands from the supermarkets. The responses have been as varied as autism itself.”<sup>1</sup>

## What we need to find out: Research recommendations

Mental health was already the **number one research priority** for autistic people, families and researchers.<sup>34</sup> While adaptations will have to be made because of the pandemic, many autistic people are keener than ever to take part in research.<sup>31</sup> Key questions include:

“Being offered a phone call, when using the phone is stressful and anxiety-making, often isn’t helpful, leaving many of us without essential support”<sup>25</sup>

- What impact have emergency changes to education, health and care systems had on the physical and mental health of the most vulnerable in society? How can we mitigate this impact as guidance changes?
- How does the accessibility, acceptability and effectiveness of digital assessment, treatment and care vary amongst neurodivergent people and across different platforms?<sup>20,26,32</sup>
- How can trauma-informed approaches to mental health support be adapted for neurodivergent people?
- How can we develop effective neurodevelopmental and mental health service models that can vary their capacity and delivery methods in response to local lockdowns or changes in national public health guidance?<sup>7,26</sup>
- How can we most effectively involve neurodivergent people in research amid social distancing measures?<sup>31</sup>

## What we should do now: Policy recommendations

- **NHS Trusts should ensure that existing crisis services are accessible to people with diverse communication needs.** Shortly after the pandemic was declared, NHS England brought forward their Long Term Plan commitment to establish a 24/7 single point of access for urgent mental health support across the country.<sup>35,36</sup> Many autistic people find phone calls difficult or impossible to engage with.<sup>8,25</sup> Commissioners and providers should make available a range of contact options (including non-virtual) to ensure accessibility for those who may need these services most.
- **NHS England should work with Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) to develop plans for preventing and treating mental health conditions in neurodivergent people and ensure responsible services are sufficiently funded.** A return to pre-pandemic services will not be enough to meet rising demand, or the particular needs of neurodivergent people. Rebuilding neurodevelopmental and mental health services for a post-COVID-19 world is the ideal opportunity to include targeted emotional, behavioural, and mental health support for this group.
- **As social distancing rules become more complex, the Department of Health and Social Care and other Government departments should consider how to keep guidance clear for those who struggle with uncertainty and ambiguity.**<sup>35</sup> Some neurodivergent people have effectively remained in full lockdown, further exacerbating inequalities, due to unclear messaging, inaccessible language, variable public compliance, or harassment over rules they are unable to adhere to fully. These concerns must be addressed if we are to ensure no-one is left behind as restrictions change.
- **Schools, employers, local authorities and STPs/ICSs should assess whether their temporary changes have benefited some neurodivergent people and plan how to retain parts of those changes indefinitely.** Many autistic people have found positive aspects to lockdown restrictions, with some even reporting improvements in mental health. Rather than dropping beneficial changes in the rush to be “back to normal”, we must all learn from these experiences and build on them to create a more inclusive world. Where telecommuting and using modern technology to communicate are more accessible than traditional ways of working, they should remain a viable option; for example, being able to apply for benefits online. If further changes must be made, these should be made clear well in advance where possible.

“I have a real problem with rules not being clear. Social distancing, 1 metre or 2 metre... which is it? Because I need to know.”