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# The Impact of COVID-19 on Autistic People in the United Kingdom

## Final report

Sarah Pais and Martin Knapp



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## Executive summary

### Purpose

The aim of this rapid research was to examine the impact of COVID-19 on autistic people (of all ages) and their families within the United Kingdom, and identify how to mitigate any adverse consequences.

### Key findings

**Every autistic person is different. This diversity is reflected in the range of experiences described in this report.**

**Communication from government:** Government communication regarding COVID-19 was difficult to understand and follow for many autistic people. Clear communication and transparency of decision-making from government are important and can help autistic people follow advice and guidance.

**Schools and education:** Access to education for autistic children during lockdown was not consistent. Continued input from schools and maintaining contact with parents and families are vital if schools need to be closed in the future.

**Grocery shopping:** Accessing groceries during lockdown was a struggle for many autistic people. Ensuring everyone has access to necessary grocery shopping, especially vulnerable groups like autistic people, must be a priority.

**Mental health and access to medical care:** COVID-19 and its consequences affected the mental health of autistic people in a range of ways. Mental and physical health care should be accessible to all members of the population. This is particularly the case for autistic people who are more likely to have mental health problems and may find it harder to access services.

**Caring responsibilities and respite:** Renewed support for family members and carers is needed. Many were exhausted during lockdown, especially when external support and respite care were stopped or reduced.

The COVID-19 pandemic has both immediate and enduring effects. Ongoing attention to the longer-term implications for autistic people and their families is imperative; particularly in relation to educational opportunity, health, employment and social inclusion, all of which can have profound effects on quality of life.

# How COVID-19 has affected autistic people



easy  
read

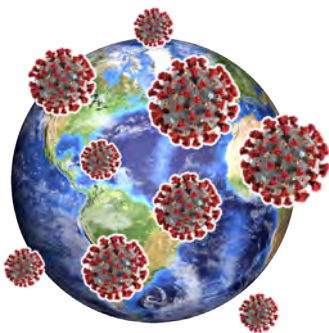
# Introduction



The Policy Innovation and Evaluation Research Unit (PIRU) helps to make rules about healthcare in the UK.



We have been doing some research to find out how **COVID-19** has affected **autistic people** and their families, and what can be done about that.



**COVID-19** is also called Coronavirus. It is a new illness that is spreading around the world. It can affect your lungs and breathing.



**Autistic people** may have difficulties with things like talking to people, being with people, or how they think and feel about things. Autism is a type of disability.



This document will tell you what we found out.



# What we found



Every autistic person is different. They are all affected by things differently.

COVID-19 has affected autistic people in many different ways, including to do with:

- education
- health
- jobs
- being included and not being alone.



We need to make sure we think about these things so that autistic people can live good lives.



## Communication from the government

**Communication** is the way people are given information. It includes speaking and writing.



We found that communication from the government was difficult to understand for most autistic people.



Communication from the government needs to be clearer to help autistic people follow advice and guidance.



## Schools and education

Autistic children did not always have access to education during COVID-19.



If schools are going to be closed in future, they need to stay in contact with the parents and families of autistic children.



## Grocery shopping

Shopping for groceries was very difficult for many autistic people during **lockdown**.



**Lockdown** is when everyone had to stay at home and most businesses were closed because of COVID-19.



We need to make sure everyone has access to grocery shopping, especially if they need extra care and support like autistic people.



## Mental health and medical care

COVID-19 affected the mental health of autistic people in many different ways.



Mental and physical health care should be available to everyone.



This is very important for autistic people as they:

- are more likely to have mental health problems
- might find it harder to access health and care services.



## Help for family members and carers

Help and support for family members and carers of autistic people needs to start up again.



Many family members and carers were very tired during lockdown because there was not as much support and **respite care**.



**Respite care** is when you get care from someone else for a short time to give your normal carer a break.



## Introduction

The Policy Innovation and Evaluation Research Unit (PIRU) was asked by the Department of Health and Social Care (DHSC) to look at the impacts of COVID-19 on autistic people of all ages and to identify ways to manage or mitigate any adverse consequences of COVID-19 on this group and their families.<sup>1</sup> This study was conducted within PIRU by the authors, based in the Care Policy and Evaluation Centre at the London School of Economics and Political Science.

We examined the relevant emerging evidence available to date. Clearly, we could not comprehensively cover how *all* autistic people in this country are experiencing the pandemic. We may never know this as there are those who struggle to have, or may never have, a voice in this discourse: there are invariably gaps in our knowledge of the impacts. Some of these gaps match broader evidence limitations on autistic people and families that were present before the pandemic.<sup>2</sup>

Autistic people can experience persistent difficulties in social interaction and communication, they may have rigid or repetitive behaviours, restricted interests, and may be resistant to change. They can also face challenges in education settings, in gaining and maintaining employment, and in initiating and sustaining social relationships. Some may have sensory difficulties or behaviours perceived as challenging or distressed. A high proportion of autistic people have mental health problems, with anxiety and depression especially prevalent. Autistic people may also have learning disabilities.<sup>3</sup>

We recognise that every autistic person is an individual. Many people lead completely independent lives and their autism may be invisible to those around them. Some individuals will need ongoing social or health care support, and some require no external help or support. Some people live alone, some with families, while others live in supported accommodation or in larger congregate care settings.

We know that the COVID-19 pandemic and the responses to it, including lockdowns, have affected different people in different ways. Many of those effects will be shared by both autistic people and people who are not autistic. However, autistic people may experience the same changes in distinct, often more pronounced ways.

1. The request to PIRU to conduct this rapid study was received in mid-June 2020. We submitted an initial report to DHSC on 31 August 2020; this was disseminated to various stakeholders and groups, and feedback was received. An updated report was provided on 3 November 2020, incorporating further evidence to that point. A revised report was submitted on 30 December 2020, and discussed with groups convened by DHSC before we completed this edited version in April 2021.

2. Russell et al (2019); McCoy et al (2020); Lemmi et al (2017)

3. National Institute for Health and Care Excellence (2012, updated 2016)



## Methods

We performed a rapid literature search including research papers, policy documents, discussion papers and reports from third sector and other bodies, and articles in the mainstream media. Due to the sudden and rapid pace of the pandemic there was a scarcity of peer-reviewed publications regarding this topic. We have therefore used a wide variety of other types of evidence. This includes involvement of an insight group<sup>4</sup> of autistic people and family members (organised with the help of Autistica, a national autism research charity), engaging with national autism charities and providers of services, linking with teams currently undertaking research, liaising with other experts including some with lived experience of autism, and searching social media.

The quality of the available evidence is variable, but we see some common themes running through completed and ongoing studies, as well as through informal conversations with autistic people, researchers, and professionals who work in services or link with autistic people (including clinicians). It should be noted that participants in the insight group and online surveys are self-selecting, and that some individuals find it easier than others to access and engage with the technology necessary for participation. Findings therefore may not be representative of the experiences or views of all autistic people.

We have inserted some quotes in the text, taken from our discussions with the people mentioned above, including with the insight group.

## Terminology

We use the term ‘autistic people’ rather than ‘people with autism’ wherever possible in this report, as this is regarded as the most accepted and preferred terminology in the United Kingdom (UK).<sup>5</sup> We do recognise, however, that there may be other preferred terms.<sup>6</sup>

4. The insight group was organised by Autistica and consisted of six autistic people (three of whom were also parents of autistic children). The insight group met remotely on 20 August 2020 with follow up in October and November 2020.

5. Kenny et al (2016)

6. Ambitious about Autism (2020); Autism Europe (2020); National Health Service (2019)





## Findings

We identified a number of (overlapping) themes and topics, which we used to structure our findings.

- Communication from government
- Schools and education
- Return to school
- Concerns over loss of skills
- Supported living
- Grocery shopping
- Access to medical care and other services
- Mental health
- Caring responsibilities and respite
- Congregate care settings
- Social isolation
- Modes of interaction
- Employment and housing
- Mortality (including suicide)
- Black, Asian and other ethnic minority groups
- Abuse
- Human rights and inequalities

### Communication from government

Communication from government during the pandemic was felt to be poor.<sup>7</sup> This was highlighted both by the insight group and in wider literature and surveys. Government messages were found to be difficult both to understand and follow,<sup>8</sup> and rule changes were confusing.<sup>9</sup> Autistic people in the insight group felt strongly that if the message was not coherent or did not make sense, it was almost impossible for them to follow. In addition, written instructions for the COVID-19 test were challenging to understand.<sup>10</sup> There was a perception of a lack of ‘easy-read’ material similar to that provided to autistic people for other uses or in other communications.<sup>11</sup> Even when such advice did exist, people were not necessarily aware of its existence nor did they always find it accessible.<sup>12</sup> The insight group recommended that advice and guidance should be clear, easy-to-read and ‘autism-friendly’ (possibly by including autistic people in the preparation process). They also felt the national press briefings should be in a format that allows people to access the information discussed more easily.<sup>13</sup>

*“... This comes now after yesterday’s announcement of a renewed national lockdown. I strongly feel the manner in which these press briefings, especially the content of their slides, which is inaccessible and excludes not just those who need adjustments, but I should think the wider public at large. There must be people who can translate the information to a simplified format...”*

Stress and anxiety often resulted from unclear rules and recommendations, especially when people wanted to follow the rules correctly.<sup>14</sup> In the early stages of lockdown one support team had to write numerous and repeated letters to the adults they were supporting to clarify that they were allowed to exercise more than once a day, as many were too frightened to leave their homes as they believed they were breaking the rules.<sup>15</sup> There were additional cases of people scared to go out because the lockdown rules were found to be hard to interpret and they feared unintentionally infringing them, with the subsequent risk of police involvement.<sup>16</sup> Inadequate government communication appears to be a theme internationally.<sup>17</sup>

7. den Houting (2020); Insight group (2020); Oomen et al (2020)

8. Insight group (2020)

9. Autism in Mind (2020)

10. Insight group (2020)

11. NHS England (2020); Twitter (July 2020)

12. Oomen et al (2020)

13. Insight group (2020)

14. Oomen et al (2020)

15. Autism in Mind (2020)

16. Autism in Mind (2020)

17. Cassidy et al (2020); den Houting (2020); Oomen et al (2020)



*“It felt like autistic people were an afterthought to the effects of lockdown. Yes, some have found it OK, or even beneficial, but some have suffered with it. The rules being very unclear for a lot of the time was very difficult for me. At one point, I stayed in for over a week as I’d become paranoid about getting the rules wrong and being arrested or upsetting members of the public and not knowing why. I’m sure I can’t have been on my own in that.”*

A study of autistic adults identified that clearer government guidelines and advance warning of changes would help autistic people. They also felt that a gradual lifting of restrictions would help individuals readjust. These themes were also mentioned by the non-autistic comparison group in that study, suggesting that this would be beneficial for everyone (i.e., both autistic people and those who are not autistic).<sup>18</sup>

## Schools and education

The importance of school as a space for learning, stimulation, structure, emotional containment and respite was evident from listening to and reading about the experiences of children and their families.<sup>19</sup> Overall experiences appear to be varied and diverse, with much depending on the individual establishment, specific teachers or auxiliary staff, the circumstances of the child and family and any additional support that remained available.<sup>20</sup> Some schools were very supportive, some had no contact with autistic pupils during lockdown, and some (including special schools) continued to operate during lockdown.<sup>21</sup>

A survey of children with special educational needs (the majority of whom were autistic) conducted early in the pandemic found considerable differences in parental satisfaction with the support provided to families during the lockdown.<sup>22</sup> Similar results were found in another study of only autistic children: just over a half of the families still had access to at least one type of specialist support during lockdown, although this was not always felt to be timely or sufficient.<sup>23</sup> Another study carried out later in the pandemic underlined that support for distance-learning was variable in both mainstream and specialist schools, and that families reported benefits when therapeutic support continued and support from school was comprehensive.<sup>24</sup>

Within the insight group, a family whose autistic child attended a mainstream school approached the school for educational assistance as they had received no contact from the school during lockdown. No help was subsequently given, with the explanation that it was ‘tough for everyone’.<sup>25</sup> Similarly, another mother was upset by the absence of communication from her child’s school, especially after she explained to them that she was autistic and required lots of information in order to make decisions. It was also noted that many parents felt a sense of shame when they asked for more help or greater clarity. This had the effect, in the words of one mother, of ‘shutting me down’.<sup>26</sup>

Parents in the insight group all hoped for some regular communication, whether the school was mainstream or specialist. Regular contact from school through telephone calls, support from a special educational needs coordinator and resources for home learning were all described as important means of support during lockdown.<sup>27</sup>

One mother spoke of the school ‘washing their hands’ when it came to supporting her child. However, the educational psychologist attached to the school remained in contact of her own volition as she feared the child’s mental health would deteriorate during lockdown. The loss of specialist input that some children usually received (such as educational psychology, speech and language therapy) was particularly felt by parents.<sup>28</sup> Difficulties engaging in services remotely were also reported to be a problem.<sup>29</sup>

18. Capp et al (2020)

19. Insight group (2020); Pavlopoulou et al (2020)

20. Insight group (2020); Pavlopoulou et al (2020); Shepherd and Hancock (2020); Autism Information and Advice (2020)

21. Insight group (2020); Palmer et al (2020); Pavlopoulou et al (2020)

22. Toseeb et al (2020)

23. Pavlopoulou et al (2020)

24. Palmer et al (2020)

25. Insight group (2020)

26. Insight group (2020)

27. Shepherd and Hancock (2020); Insight group (2020)

28. Insight group (2020); Palmer et al (2020)

29. Ambitious about Autism (2020); Palmer et al (2020)





Risk assessments were highlighted as a potential barrier to access education. The House of Commons Education Committee, sitting in July 2020, heard that risk assessment procedures were sometimes being used as a ‘blanket excuse’ to prevent children with special educational needs from re-accessing educational settings.<sup>30</sup> The Committee was concerned with all children and young people with special educational needs and not specifically with autistic children, but their findings provide a sense of what an autistic child may experience, as a large number of children with special educational needs are autistic. A survey of parents of children with special educational needs found that many reported that either no risk assessment had been conducted or that they did not know if one had been conducted.<sup>31</sup> Parental perception was that risk assessment could be used as a tool to prevent or dissuade families from returning their children to school.<sup>32</sup> Children who were on Education Health Care Plans (of whom many would be autistic) were deemed by government to be vulnerable and therefore could access schooling during the lockdown period.<sup>33</sup> However, only a small number actually did so.<sup>34</sup> This may be due in part to challenges with access to school placements.<sup>35</sup>

In contrast to these problems, many other parents have described exemplary experiences of home-schooling during lockdown.

*“His school have provided a wonderful home-school learning experience ...with teaching assistants available during each lesson, speech and language therapy available once a week for parents and children. He’s worked harder and learnt more in lockdown than he would have done at school.”*

One family spoke of the much-needed respite and psychological containment provided by their child’s special school, which continued to function during lockdown.<sup>36</sup> This feeling was reiterated in a survey of children with special educational needs which reported that many parents described schools as ‘incredibly supportive’.<sup>37</sup>

## Return to school

Many children and parents were apprehensive about the return to school at the start of the new academic year. For some parents, this was related to the recognition that their child had been happier and more relaxed at home during lockdown and the school holidays.<sup>38</sup> Within the insight group, concerns regarding new and unfamiliar rules in schools caused some anxiety, and it was felt that children and their families needed information as early as possible to help them prepare.<sup>39</sup> There were also worries that children may struggle to return to school after such an extended period away.<sup>40</sup>

A survey by Ambitious about Autism reported that the majority of autistic children and young people were worried about returning to school, college or university. This included concerns that appropriate support would not be in place, worries about being unsafe due to COVID-19 and apprehension about catching up with studies. Children and parents in this survey described losing sleep from worry about the return to education.<sup>41</sup>

For other families, the return to school was welcomed ‘because of the increasing challenging verbal and physical behaviours shown at home’.<sup>42</sup> Many parents of children with special educational needs found it particularly challenging to educate their child at home.<sup>43</sup> They were also concerned about the long-term impacts of the lockdown on their children’s mental health, as well as their social and academic progress.<sup>44</sup>

Impressions from a return to school survey of disabled children (including autistic children) conducted in the autumn of 2020, suggest that children were still able

30. House of Commons Education Committee (2020)  
 31. Tirraoro et al (2020)  
 32. Children’s Commissioner (2020); Tirraoro et al (2020)  
 33. Children’s Commissioner (2020)  
 34. Children’s Commissioner (2020); Department for Education (2020)  
 35. Palmer et al (2020)  
 36. Insight group (2020)  
 37. Shepherd and Hancock (2020)  
 38. Shepherd and Hancock (2020)  
 39. Insight group (2020)  
 40. Children’s Commissioner (2020)  
 41. Ambitious about Autism (2020)  
 42. Shepherd and Hancock (2020)  
 43. Tirraoro et al (2020)  
 44. Shepherd and Hancock (2020)



to access school adequately, but access to wider services such as mental health, transport, social care and therapies continued to be problematic.<sup>45</sup> There were also reports in the mainstream media that some children with special educational needs, including autism, were unable to access school due to compliance with new infection control guidelines.<sup>46</sup> It is likely that these barriers to access were not related specifically to autism but to other medical conditions and their management (such as tracheostomies).

*“...[He] looked forward to returning to school. He missed his friends and teachers. He missed school routine.*

*Within a week of returning to school he realised his school routine had changed for COVID reasons – temperature checks, bubbles, washing hands etc. – and he was tired at the end of a day.*

*He has worn a mask on local authority transport to and from school to keep himself and others safe. He understands and follows COVID rules.*

*He has had a good 8 weeks back to school and his school report for the term was really positive.*

*He is in a good place. His school has plans in place to support the children if they need to shield or take time to quarantine.*

*I feel happy and confident about the next term.”*

## Concerns over loss of skills

Parents described their children ‘regressing’ after not going to school for several months.<sup>47</sup> They were concerned that previous developmental and educational gains would be lost.<sup>48</sup> There was a sense that an autistic child will find it harder to recover compared to their peers who were not autistic.<sup>49</sup> There were also worries that the loss of social skills (as there had been no opportunity to practice) may have repercussions for the child’s future.<sup>50</sup> Skills such as turn-taking, sharing, group activities and diverse conversations may not have been possible to develop within the home.<sup>51</sup> There were also concerns over deterioration in friendships, due to not being able to meet as a result of COVID-19 restrictions, especially as some autistic children may only have a small number of friends.<sup>52</sup>

These concerns also extended to autistic adults. Providers of services expressed apprehension that during lockdown autistic adults were starting to lose life skills they had developed, and autistic people themselves specifically described losing the social skills that they have worked hard to develop over time.<sup>53</sup>

*“...I know from going out back in August, it was blocked with cars near the beach and rules in many cases were flouted...”*

*Luckily, those I live with are still in work and one was able to land another job after being made redundant, but I feel it is going to be a struggle for myself for job vacancies on the market now. In one case, there were 100 applicants and I was lucky to progress to a shortlist, but it’s not great to be competing with those who are only just being made redundant and have the right criteria for another similar role.*

*If I’m honest, I don’t miss much of travelling on trains or going far and wide. I’ve been quite content at home.”*

45. Disabled Children’s Partnership (2020a)

46. Guardian Newspaper (2020)

47. Insight group (2020)

48. Insight group (2020)

49. Insight group (2020); Ambitious about Autism (2020)

50. Insight group (2020); Shepherd and Hancock (2020)

51. Shepherd and Hancock (2020)

52. Palmer et al (2020)

53. Insight group (2020); Warren and Giles (2020)



## Supported living

To provide an illustration of how the pandemic has affected autistic people within supported living arrangements in the UK, we have used the experiences and reflections during lockdown of two providers of supported living from different parts of the country. Put together, they provide services for over 600 autistic adults living in the community with a range of daily supports.<sup>54</sup> Again, a varied picture was described: some people ‘flourished’ with the changes that lockdown brought, while for others it was challenging.<sup>55</sup> There was a feeling that good providers will find a way to manage in order to support autistic people appropriately, but other organisations may struggle.<sup>56</sup>

The initial consequences of lockdown were positive for some autistic people, and there was a surprise to see such a large number of people who benefitted from the changes. Due to the restrictions introduced in lockdown (for example, reduced choices available in relation to activities and less opportunity to venture outside), less distressed behaviour and reduced stress and anxiety were observed, and many people were felt to be much calmer. Incidents of distressed behaviour may have dropped because of the reduced demands placed on autistic people as a result of lockdown.<sup>57</sup>

Many autistic people coped unexpectedly well with the changes in routine. This may have been helped by greater continuity in staff support: there were fewer staffing changes, necessitated by the infection control restrictions introduced in response to the pandemic. This meant there was a smaller staff team looking after every person and no leave for staff during the period of lockdown. However, this type of working would not be sustainable in the longer term and would bring challenges from more dependence on a smaller number of staff.<sup>58</sup>

Other autistic people did not have such positive experiences. Many ‘felt trapped inside of their homes’ with a need to ‘get out to enable them to regulate’.<sup>59</sup> For one autistic adult, the inability to see his family started ‘a downhill decline in mental health’, with ‘increased anxiety and a rapid intensification in self-injurious behaviour’ that resulted in a hospital admission.<sup>60</sup> There were also reports of autistic people with less complex needs feeling isolated and withdrawn.<sup>61</sup> Many did not want to access support through technology, but they were also unable to access their usual community services and supports.<sup>62</sup>

Anxiety levels in some autistic people were found to be heightened at the beginning of lockdown, initially with concerns about the virus itself, then subsequently with every rule change. There was a marked increase in adults accessing ‘lower-level preventative support’.<sup>63</sup> A rise in health-related anxieties, with more people requiring reassurance about their general health, was also observed. This same provider also noted an increase in ‘meltdowns’, both in terms of frequency and duration.<sup>64</sup>

Wearing a face covering or mask is known to be problem for some autistic people, as well as a source of anxiety.<sup>65</sup> Within the two supported living communities, there were notably different responses to mask-wearing; with some autistic people diligently wearing masks (and wanting mask-wearing to be enforced uniformly for everyone), while others were unable to wear a face covering due to sensory or other issues. Again, this highlights the variety of individual needs and the differences of experiences and impacts in the autistic community.

54. Autism in Mind (2020); Kingwood (2020)

55. Kingwood (2020); Autism in Mind (2020)

56. Kingwood (2020)

57. Kingwood (2020)

58. Kingwood (2020)

59. Autism in Mind (2020)

60. Kingwood (2020)

61. Kingwood (2020)

62. Autism in Mind (2020)

63. Autism in Mind (2020)

64. Autism in Mind (2020)

65. Autism in Mind (2020)



## Grocery shopping

There were countless reports of difficulty obtaining groceries.<sup>66</sup> A National Autistic Society survey<sup>67</sup> reported that buying food was the biggest difficulty for autistic people during lockdown.<sup>68</sup> This finding was replicated in another survey early in the first national lockdown, where issues related to groceries was the most often reported anxiety-provoking topic for autistic adults.<sup>69</sup> This was due to disrupted shopping routines, the unavailability of products and the introduction of new rules.<sup>70</sup>

Many of the people in the insight group were already set up with online shopping prior to lockdown because of the difficulties and stress they experience when shopping in person. During the lockdown, several of the pre-existing online grocery shoppers were unable to access delivery slots. Even after contacting supermarkets to explain the problem, they only received limited help. One suggestion was that supermarkets should have a separate list of people who may not be medically at risk but have other vulnerabilities, including autistic people who may find access difficult.<sup>71</sup> However during the lockdown those who were considered medically vulnerable (and were recorded on the register of vulnerable people communicated to supermarkets) also struggled to gain access to slots.<sup>72</sup> Some autistic people only eat certain foods (perhaps due to sensory sensitivities) and getting hold of these specific products was challenging for many.<sup>73</sup>

Another problem highlighted was the different types of infection control arrangements put in place by different supermarket chains. This again caused anxiety for some autistic adults.<sup>74</sup> There were also multiple instances of shops refusing to make reasonable adjustments for those without a visible disability (even if they were carrying documentation or cards to the contrary).<sup>75</sup>

For the autistic people who were able to shop in person, some found it a more pleasant, less stressful experience due to the quietness.<sup>76</sup>

*“I did the majority of our shopping, and found it much more relaxing than usual. The queues outside were a good time to read, with no one too close, though I was concerned so few people wore masks – it is such a good protection for others and also provides the wearer an amount of protection.”*

## Access to medical care and other services

Unmet medical need has previously been identified as a problem for autistic people.<sup>77</sup> This issue was reflected in a survey of parents which reported a high level of difficulty accessing health care both before and during lockdown.<sup>78</sup> A supported living provider also reported that accessing health care, including booking appointments, had also been problematic.<sup>79</sup> Findings from a survey of health and education professionals suggested that autistic individuals experienced a disruption to services as a result of the pandemic, with some experiencing a complete loss of services.<sup>80</sup> Similar responses came from a survey of autistic people and carers, with one respondent additionally highlighting the lack of communication about the closure of a local diagnostic service.<sup>81</sup> Concerns have been raised on a national level that the pandemic will increase waiting times for an autism diagnosis.<sup>82</sup>

Another study, which reviewed health and social care policies of European countries and analysed survey data on autistic people and people with learning disabilities (and their carers), found significant barriers to accessing COVID-19 services. These included a lack of COVID-19 testing, inaccessible treatment services (largely due to communication needs), discriminatory intensive care protocols and changes to health and social care that caused interruptions to both support and provision of services.<sup>83</sup>

66. Insight group; Oomen et al (2020); Pavlopoulou et al (2020)

67. Conducted in partnership with Ambitious about Autism, Autistica, Scottish Autism, and the Autism Alliance.

68. National Autistic Society (2020c)

69. Oomen et al (2020)

70. Insight group (2020); Oomen et al (2020); Pavlopoulou et al (2020)

71. Insight group (2020)

72. Twitter (2020)

73. Insight group (2020); Palmer et al (2020); Pavlopoulou et al (2020)

74. Autism in Mind (2020)

75. Autism in Mind (2020)

76. Realpe et al (2020)

77. Croen et al (2015); World Health Organization (2019)

78. Pavlopoulou et al (2020)

79. Autism in Mind (2020)

80. Spain et al (2020)

81. Autism Information and Advice (2020)

82. British Medical Association (2020); Reddy (2020)

83. Oakley et al (2020)



There were many reports of autistic people and their families being distressed over issues including access to management, artificial ventilation, Do Not Attempt Cardiopulmonary Resuscitation (DNAR CPR) decisions and National Institute for Health and Care Excellence (NICE) frailty scores.<sup>84</sup>

Autistic people in the insight group reported exemplary access to medical care. For example, one family needed to take their autistic child to the accident and emergency department during lockdown because she had a seizure. They were very satisfied with both the access to and quality of care received. People in the insight group were, however, worried about any potential in-patient admission to hospital, especially in circumstances where no visitors would be allowed. They were concerned about how they would be able to communicate their needs to staff, and many felt they would struggle to do so without the support of a family member or friend present.<sup>85</sup>

Autistica has called for the use of text-messaging for mental health services to improve access for autistic people who struggle with conventional means of access.<sup>86</sup> The success of new technologies in health care during the pandemic was deemed to be contingent on cohesive infrastructure, clear policies, adequate equipment and time.<sup>87</sup>

## Mental health

The COVID-19 pandemic and its consequences affected people's mental health in numerous ways. This is evident in the marked heterogeneity of the experiences of autistic people. Many described the detrimental impacts to their mental health, while others experienced mental health improvements from the lockdown.<sup>88</sup> For example, not going to school or socialising brought relief to some, while unpredictable change and uncertainty brought stress and worry to others.<sup>89</sup> As the pandemic progresses, we may see changes in the types of mental health problems that people experience.

Anxiety was the main mental health difficulty described in the insight group, which was echoed in national and local surveys.<sup>90</sup> Anxiety has also been touched upon in the other themes in this report. Observing and adhering to rules correctly, adapting to changing rules and practising new infection control measures such as face masks and social distancing all increased levels of anxiety in autistic people. Coming out of lockdown, reintegrating with the world and following a new set of social norms and rules were also a cause of anxiety. The ongoing uncertainty of the situation meant that all the psychological protection of planning could not be harnessed.

One parent in the insight group spoke of their child being so scared of contracting COVID-19 that he remained at home during the entirety of the first national lockdown. One provider of supported living services also described the high amount of anxiety generated over COVID-19 itself, with several autistic people 'obsessing about transmission rates' and worrying about both themselves and their families contracting the disease.<sup>91</sup>

This was mirrored in another study of autistic adults, where a small number of people reported feeling concerned enough about becoming infected with COVID-19 and so avoided going out at all at the beginning of lockdown.<sup>92</sup> An additional survey found lower quality of life scores and higher depression and anxiety scores in autistic adults compared to a control group who are not autistic.<sup>93</sup> Autistic people frequently mentioned a greater need for additional mental health support, but also emphasised that this lack of support preceded the current pandemic.<sup>94</sup>

Children also experienced mental health problems. One study early in the pandemic found a high prevalence of emotional and behavioural difficulties in all children, but particularly in those with neurodevelopmental disorders (including autism).<sup>95</sup> Conduct

84. Cassidy et al (2020); Pavlopoulou et al (2020)  
 85. Insight group (2020)  
 86. Harper et al (2020)  
 87. Spain et al (2020)  
 88. Spain et al (2020)  
 89. Spain et al (2020)  
 90. Capp et al (2020); National Autistic Society (2020c); Autism Information and Advice (2020)  
 91. Kingwood (2020)  
 92. Realpe et al (2020)  
 93. Capp et al (2020)  
 94. Capp et al (2020)  
 95. Nonweiler et al (2020)





and prosocial behaviours (behaviours with an intent to benefit others) were markedly impaired in children with diagnoses of autism and attention deficit hyperactivity disorder.<sup>96</sup> Also female children with a diagnosis of autism had higher levels of emotional symptoms compared to males.<sup>97</sup> Another survey of children with special educational needs (a large proportion of whom were autistic) found that many parents and children experienced worry and other changes in mood and behaviour.<sup>98</sup> There were some parents who also described feeling overwhelmed.<sup>99</sup> For a minority of families in this survey, there was little reported impact on mental health, and in a few cases there were improvements in mental health.<sup>100</sup>

Disruption of established routines as a result of the pandemic was identified as a cause of both emotional and behavioural problems in both adults and children.<sup>101</sup> This may also be exacerbated by a limited understanding of the situation, particularly in children, and the potential loss of access to regular supports.<sup>102</sup> Lockdown interfered with daily routines that provided a feeling of safety and security, thereby increasing anxiety levels.<sup>103</sup> In addition, some autistic people were preoccupied by the impending lifting of lockdown restrictions.<sup>104</sup> This was because they anticipated a fresh wave of rapid changes to their newly adjusted routines.<sup>105</sup>

*“The feeling that all of the ‘social rules’ seem to have changed – and to be continuing to change – almost overnight... I feel like I just don’t know how to behave or what to expect from people any more.*

*That when I do venture out to try and establish a way of doing things that I can cope with, by the time I try again a week or two later everything has changed again – different rules, different layouts in the supermarket etc. So rather than being able to gradually build my confidence to going out, I am finding I am back at square one again.*

*I feel I have lost some of my independence and am struggling a bit with my mood and anxiety levels due to frustration with myself and feeling increasingly unproductive and cut off from society.*

*My local autism group has also resumed meeting on Zoom which is a huge help and I have met up with my two best friends in the last week, which has given me both a reason and the confidence to leave the house for a couple of hours and – I think – did me the power of good those days.”*

Another wider thread that was evident was the benefits that many autistic people derived from the new lifestyle that lockdown imposed.<sup>106</sup> Lockdown provided an environment where people had the ‘freedom to deviate from society’s expectations’<sup>107</sup> and where they did not have to conform to societal norms.<sup>108</sup> They could, for example, spend much more time on specialist interests, which may not have been possible prior to lockdown.<sup>109</sup>

People could also work at their own pace doing daily activities, and many appreciated the slower pace of life.<sup>110</sup> Eased social expectations had the effect of decreasing anxiety.<sup>111</sup> Many families also reported reduced anxiety and stress because they faced less evident stigma and discrimination during lockdown (because of the reduced time spent in public).<sup>112</sup>

Interviews with autistic adults revealed that, prior to COVID-19, many had developed strategies and built resilience to cope with uncertainty.<sup>113</sup> During the pandemic they were able to leverage these skills.<sup>114</sup> Exercise was also found to be a very helpful coping mechanism for many people: had this not been allowed during lockdown, they would have struggled.<sup>115</sup>

96. Nonweiler et al (2020)  
 97. Nonweiler et al (2020)  
 98. Asbury et al (2020)  
 99. Asbury et al (2020)  
 100. Asbury et al (2020)  
 101. Cassidy et al 2020; Esraghi et al 2020  
 102. Cassidy et al 2020; Palmer et al (2020)  
 103. Realpe et al (2020)  
 104. Realpe et al (2020)  
 105. Realpe et al (2020)  
 106. Insight group (2020)  
 107. Oomen et al (2020)  
 108. Oomen et al (2020); Pavlopoulou et al (2020); Realpe et al (2020)  
 109. Oomen et al (2020); Pavlopoulou et al (2020); Realpe et al (2020)  
 110. Realpe et al (2020)  
 111. Oomen et al (2020); Realpe et al (2020)  
 112. Pavlopoulou et al (2020)  
 113. Realpe et al (2020)  
 114. Realpe et al (2020)  
 115. Insight group (2020)



A survey of parents reported that autistic children experienced a reprieve from attending school, and were much happier at home.<sup>116</sup> This finding was reiterated in a survey of parents of children with special education needs, where parents noted that children had thrived without the pressures of school.<sup>117</sup> Home was felt to be a safe and happy place where they could spend one-to-one time with family members.<sup>118</sup> There was relief from outside expectations held by their teachers or classmates.<sup>119</sup> Other reasons why children were less stressed and anxious at home included being away from dealing with bullies and the experience of being left out of friendship groups, not having to wear school uniform and having breaks when needed.<sup>120</sup>

This last point emphasises the importance of personal autonomy, which is shared with adults in the workplace.<sup>121</sup> One mother also described her child having a ‘masking-break’<sup>122</sup> during lockdown.<sup>123</sup> More activities shared as a family took place, including for play and leisure.<sup>124</sup> A large survey of children and young people looked at a subset with special education needs and found that parents reported a reduction in their child’s emotional difficulties, with no change in behavioural or attentional difficulties during lockdown.<sup>125</sup>

## Caring responsibilities and respite

Exhaustion was described by many of the parents in the insight group who cared for and home-schooled their autistic children during lockdown.<sup>126</sup> They felt they had to work much harder in order for their autistic child to feel safe and contained. One mother described it being ‘easier to home-school the other children’ compared to her ‘autistic child’.<sup>127</sup> Parents needed to take on multiple additional roles in lockdown which could be challenging.<sup>128</sup> Families struggled to access respite and experienced knock-on effects on their mental health.<sup>129</sup> There was also a worry about ageing carers: what happens when the people who are the main carers for autistic people become ill or frail?<sup>130</sup>

Service provision and respite care during lockdown were described as patchy and fragmented.<sup>131</sup> Social distancing requirements in day services and transport to those services restricted capacity, reducing the numbers of people who could access services and the amount of time spent there.<sup>132</sup> A survey of families with disabled children (some of whom had a diagnosis of autism) found that families reported that there had been cuts to services, delays in health and social care assessments, and reductions in support (including therapies) as a result of easements to the Care Act 2014 consequent to the Coronavirus Act 2020.<sup>133</sup> A number of organisations expressed concerns to the Social Care Sector COVID-19 Taskforce that, although local authorities may not have applied easements, Care Act duties may still have been subject to prioritisation.<sup>134</sup>

Many families with disabled children were providing more care for their child subsequent to lockdown (this included siblings providing care).<sup>135</sup> A separate parental survey looking specifically at the siblings of disabled children (including children with a diagnosis of autism) shed a further light on the effects of lockdown on siblings. Parents reported being unable to take the sibling physically away from the home while the disabled child was having a ‘meltdown’.<sup>136</sup> The lack of respite or opportunity for breaks was also felt by parents to have a significant impact on siblings.<sup>137</sup>

A broader survey looking at carers in general (including carers of autistic people) found reports of high levels of fatigue and stress, as well as widespread accounts of feeling exhausted and worn out.<sup>138</sup> Many carers reported that they were providing more care and that they had reduced their working hours (in their paid employment) so as to manage additional caring responsibilities.<sup>139</sup> The National Autistic Society survey also reported that family members of autistic people had to reduce work due

- 116. Pavlopoulou et al (2020)
- 117. Shepherd and Hancock (2020)
- 118. Shepherd and Hancock (2020)
- 119. Pavlopoulou et al (2020)
- 120. Shepherd and Hancock (2020)
- 121. Insight group (2020)
- 122. Masking is when autistic people ‘invest considerable effort daily in monitoring and modifying their behaviour to conform to conventions of non-autistic social behaviour’. Other terms used include: ‘social camouflaging’, ‘pretending to be normal’, and ‘pretending to not be autistic’. See Mandy (2019).
- 123. Insight group (2020)
- 124. Pavlopoulou et al (2020)
- 125. Percy et al (2020)
- 126. Insight group (2020)
- 127. Insight group (2020)
- 128. Autism Information and Advice (2020); Spain et al (2020)
- 129. Evening Standard (2020)
- 130. Insight group (2020)
- 131. Spain et al (2020)
- 132. Department of Health and Social Care (2020)
- 133. Disabled Children’s Partnership (2020b)
- 134. Department of Health and Social Care (2020)
- 135. Disabled Children’s Partnership (2020b)
- 136. Sibs (2020)
- 137. Sibs (2020)
- 138. Carers UK (2020)
- 139. Carers UK (2020)



to caring responsibilities.<sup>140</sup> The survey found that people who required constant support were significantly more affected by lockdown than those who required less assistance.<sup>141</sup> This ‘higher-need’ group and their families also reported a lack of adequate information or guidance regarding how to manage during lockdown.<sup>142</sup>

## Congregate care settings

The risks associated with living in congregate care<sup>143</sup> settings during a pandemic are shared with other population groups, including people with learning disabilities.<sup>144</sup> Pertinent issues include availability and effectiveness of personal protective equipment (PPE), testing of residents and staff for COVID-19, size and layout of care settings, staffing patterns and infection levels in the surrounding community. There are particular challenges when providing face-to-face support if there is a requirement for shielding or isolation.<sup>145</sup> For example, the National Autistic Society was particularly concerned about requirements regarding PPE, as many autistic people struggle with wearing face masks or coverings, or being supported by someone else wearing one.<sup>146</sup>

Internationally, because of the risks associated with living in congregate settings, some autistic individuals have moved back to their family home.<sup>147</sup> It is not clear to what extent this has happened in the UK. Many people living in residential care during lockdown were not able to visit their family or were not able to spend the same amount of time with their family in the usual manner.<sup>148</sup> For example, they were only able to see family members outside for a short period of time in the garden, rather than spending weekends at home.<sup>149</sup>

## Social isolation

As noted earlier, many autistic people were happier and more content during lockdown because of the reduced need for social contact. Social activity was described as functional rather than as reason to connect with others.<sup>150</sup> Reduction in these forms of interactions (which can be stressful for autistic people) was a relief during lockdown.

*“I enjoyed the lockdown...I didn’t have to see anyone.”*

*“My social needs are met by my husband and online by friends.”*

Several of the surveys reported that many autistic people were already familiar with the sort of isolated lifestyle that lockdown created for the rest of the population.<sup>151</sup> This was in part protective, in order to avoid discrimination and hostile interactions in the outside. A mother in the insight group recalled someone shouting abuse to her son at the start of lockdown as he tried to enter a toy shop which was closed. He subsequently was scared to leave the house. Furthermore, another survey reported that parents described practicing some form of social distancing prior to the pandemic due to adverse reactions from members of the public to their autistic child and their behaviours.<sup>152</sup> Specialist autism teams have also been concerned with the verbal abuse received by autistic people from the general public.<sup>153</sup>

We also know that, prior to the pandemic, many autistic people were lonely and craved social contact, but found the intricacies of navigating social interaction inherently challenging. Many already lived socially isolated lives for multiple reasons, including overstimulation, social exclusion and stigma.<sup>154</sup> Autistic people who live on their own without family or support structures are known to face increased or disproportionate risk of mental health problems, especially anxiety.<sup>155</sup> There are concerns that the pandemic has exacerbated this already entrenched isolation.

<sup>140</sup>. National Autistic Society (2020c)

<sup>141</sup>. National Autistic Society (2020c)

<sup>142</sup>. National Autistic Society (2020c)

<sup>143</sup>. By ‘congregate care’ we mean any of a range of group-living settings that provide 24-hour care or supervision.

<sup>144</sup>. Comas-Hererra et al (2020)

<sup>145</sup>. National Autistic Society (2020a)

<sup>146</sup>. National Autistic Society (2020a)

<sup>147</sup>. Ameis et al (2020)

<sup>148</sup>. National Autistic Society (2020c)

<sup>149</sup>. National Autistic Society (2020c)

<sup>150</sup>. Insight group (2020)

<sup>151</sup>. Realpe et al (2020); Oomen et al (2020); Pavlopoulou et al (2020)

<sup>152</sup>. Pavlopoulou et al (2020)

<sup>153</sup>. Autism in Mind (2020)

<sup>154</sup>. den Houting (2020); Simmons (2020)

<sup>155</sup>. Narzisi (2020); Pellicano and Stears (2020)





The National Autistic Society survey found that autistic people were more likely to report loneliness and low life satisfaction compared with Office of National Statistics data for the general population.<sup>156</sup>

## Modes of interaction

Some autistic people can be anxious when using the telephone or using video communication.<sup>157</sup> Many experience difficulties with telephone appointments, including for the renewal of benefits and to arrange mental health support.<sup>158</sup> Some may prefer text-messaging as a form of communication.<sup>159</sup> A study of support workers described the challenges faced by some autistic people when using new technologies or modes of communication such as video conferencing.<sup>160</sup> This includes having no access to technology or the means to pay for it; for example, they may not have a smartphone, tablet or computer, or have access to Wi-Fi.<sup>161</sup> They may also struggle with interactions that use new modalities or interacting with people who wear face masks.<sup>162</sup>

One supported living provider described the anxiety caused by the inability to access services in the usual manner (as services had moved to an online platform). The autistic people they support expressed a need to see their support workers in person and also to meet with the other autistic adults face-to-face. The provider felt that this lack of ordinary physical social contact had impacted on the emotional wellbeing and mental health of many of the people it supports.<sup>163</sup>

## Employment and housing

Autistic people may be more vulnerable than other members of the population to the economic consequences of the pandemic, for reasons related to and encompassing employment status, income distribution, health and wellbeing and job satisfaction.<sup>164</sup> The immediate impact on the labour market was under-employment, but this has progressed to unemployment as business and industry sectors have been adversely affected by the pandemic.<sup>165</sup> Autistic self-advocates and others have expressed concern regarding the vulnerability of autistic people to housing-related problems (such as complications with tenancies) and have underscored the difficulties they may have with handling finances.<sup>166</sup>

Many adult autistic people want to continue working in a similar manner as they have done during lockdown, i.e. remotely and using new technologies.<sup>167</sup> They have felt comfortable working online and were already utilising technology to manage other parts of their lives before lockdown.<sup>168</sup> It is hoped by some that lockdown will enable workplaces to embrace home working more broadly.<sup>169</sup> More autonomy in the workplace will also improve their working lives.<sup>170</sup> It was noted in the insight group that the understanding and support of employers contributed to the ease with which parents were able to look after their autistic children at home, although the extent and nature of this support varied considerably between employers.<sup>171</sup>

*“Both my children have been back to full-time school, cautiously at first. Immediately, we entered self-isolation due to a simple cold and the inability of the government to provide us with a timely COVID test to release us. This caused so much frustration and I felt let down and that the government had now had several months to sort out the issue of testing and that this wasn’t fair: our children need to be educated and this felt especially annoying.*

*At first, I was afraid of COVID and, in August, was not yet fatigued and not yet angry at the government. This changed in September. I no longer respect their*

- 156. National Autistic Society (2020c)
- 157. Oomen et al (2020)
- 158. Autism in Mind (2020); Autism Strategy Executive Group, external stakeholder (2020); Autism Information and Advice (2020)
- 159. Oomen et al (2020)
- 160. Warren and Giles (2020)
- 161. Warren and Giles (2020)
- 162. Oomen et al (2020)
- 163. Autism in Mind (2020)
- 164. Heasman et al (2020)
- 165. Equality and Human Rights Commission (2020); Office for National Statistics (2020b)
- 166. Autism Strategy Executive Group, external stakeholder (2020)
- 167. Insight group (2020)
- 168. Cassidy et al (2020); Insight group (2020); Pellicano and Stears (2020)
- 169. Cassidy et al (2020); Insight group (2020); Pellicano and Stears (2020)
- 170. Cassidy et al (2020); Insight group (2020); Pellicano and Stears (2020)
- 171. Insight group (2020)



*rationales, their so-called science. I do not feel confident in them and I now resent the restrictions placed on me. COVID has lost its impact in my mind. I'm bored of it. It's not that I don't recognise how terrible it is and how many people have lost their lives. It's just I don't think the government strategy is effective and I followed all their rules and they let me down by not providing me with a COVID test for my child when it was needed.*

*I am fearful they will call a national lockdown and I can't cope with one again. Plus, now I feel resentful and angry about one because it represents the government's poor decision-making and management.*

*I cannot handle all the vagueness and not knowing. My husband is now working overseas because he could not get a job here, leaving me as an autistic mother to cope with two autistic children alone. COVID is ripping apart families and communities. I have not seen my therapist face to face since March and I desperately need to. Zoom just isn't enough. And it's the same for my autism groups. Zoom just doesn't cut it. I now feel the risk to society and myself from all these restrictions is worse than from covid itself. I need some semblance of normality again. If government could have sorted out their testing we would not be where we are.*

*I don't mind following rules when they are fair and just. The rules are no longer fair and just here in the UK. They make no sense, keep changing and I feel cheated when I follow the rules and it's still out of control."*

## Mortality (including suicide)

There are no reliable data on mortality rates for autistic people during the pandemic, although some broader findings are relevant.

Evidence from prior to the pandemic suggests that autistic people have a higher mortality rate (from all causes, including suicide) than the general population.<sup>172</sup> Analyses from a nationwide registry study in Sweden, for example, found that autistic people with a learning disability have higher mortality risk than those without learning disability.<sup>173</sup> However, the risk of suicide is higher in the latter group.<sup>174</sup>

Turning to data collected *during* the pandemic, Public Health England (PHE) reported as follows:

The key finding of this study was that people with learning disabilities had significantly and substantially higher death rates in the first wave of COVID-19 in England than the general population... Adjusting for the likely level of under-notification it was 6.3 times the general population rate.

... As in the general population, the COVID-19 death rate in people with learning disabilities was higher for men than for women. The overall increase in deaths was also greater in Asian or Asian-British, and Black or Black-British people.

Residential care homes providing care for people with learning disabilities do not appear to have had the very high rates of outbreaks of COVID-19 seen in homes providing care for other groups, mainly older people. This appears to be related to their smaller number of beds.<sup>175</sup>

These data do not distinguish between people with a learning disability and those individuals (representing somewhere between one sixth and one quarter of the learning disabled population in England<sup>176</sup>) who have a learning disability and are also autistic.

<sup>172</sup> Hirvikoski et al (2016); Cassidy et al (2014)

<sup>173</sup> Hirvikoski et al (2016)

<sup>174</sup> Hirvikoski et al (2016)

<sup>175</sup> Public Health England (2020) p.65

<sup>176</sup> Authors' calculations from Public Health England (2016), Parr and Woodbury-Smith (2018), Mackay et al (2017).



We therefore do not know whether these above-average mortality rates apply to the autistic subgroup.

The National Child Mortality Database provides real-time surveillance on child suicide rates in England. Suicides rates before and during the first national lockdown were analysed. There was no confirmed statistical finding of increased risk for autistic children during the lockdown.<sup>177</sup> Prior to lockdown, 25% of child suicides occurred in children with diagnoses of autism or attention deficit hyperactivity disorder or both.<sup>178</sup> During lockdown, 24% of all suicides in children occurred in children with these diagnoses.<sup>179</sup>

### Black, Asian and other ethnic minority groups

There is a disproportionate death rate from COVID-19 among people from Black, Asian and ethnic minority backgrounds.<sup>180</sup> We do not know the extent to which autistic people from these groups have been affected. There is a paucity of research on autistic people from minority ethnic backgrounds. The National Autistic Society has highlighted that it can be especially hard for people from Black, Asian and ethnic minority groups to get diagnosed with autism and receive the associated support.<sup>181</sup>

### Abuse

Autistic adults and children are more vulnerable to exploitation and abuse.<sup>182</sup> There are concerns about increased risk of abuse as people are confined to homes with reduced access to the usual means of support and detection.<sup>183</sup> The National Society for the Prevention of Cruelty to Children identified an increase in the risk of abuse of all children during the pandemic due to an increase in stressors to parents and caregivers, increases in children's vulnerability and a reduction in normal protective services.<sup>184</sup> Early studies looking at children in general have indicated that the effects of lockdown, including school closures, may have caused harm as abuse remained hidden.<sup>185</sup>

### Human rights and inequalities

The pandemic has implications for the rights of autistic people, especially those detained in settings such as Assessment and Treatment Units (ATUs) and other mental health hospitals. A full discourse on the human rights implications of the pandemic for autistic people is beyond the scope of this report, nonetheless it is clear that there are impacts on this group. The Joint Committee on Human Rights published a report on this matter and the Government have published a response to the report's findings.<sup>186</sup>

The Royal College of Psychiatrists provided guidance for clinicians which clarified that non-compliance or difficulty gaining compliance with any restriction and intervention required for the management of COVID-19 should not be interpreted as adequate grounds for detaining an autistic person.<sup>187</sup> There have also been concerns surrounding police interactions with autistic people during lockdown.<sup>188</sup>

<sup>177</sup>. Odd et al (2020)

<sup>178</sup>. Suicides recorded during the 82 days prior to the national lockdown in spring 2020. See Odd et al (2020).

<sup>179</sup>. Suicides recorded during the first 56 days of the national lockdown in spring 2020. See Odd et al (2020).

<sup>180</sup>. Office for National Statistics (2020a); National Institute for Health Research (2020)

<sup>181</sup>. National Autistic Society (2020b)

<sup>182</sup>. Social Care Institute for Excellence (2020)

<sup>183</sup>. Pellicano and Stears (2020); Social Care Institute for Excellence (2020)

<sup>184</sup>. National Society for the Prevention of Cruelty to Children (2020)

<sup>185</sup>. Garstang et al (2020); Sidpra et al (2020)

<sup>186</sup>. Joint Committee on Human Rights (2020); UK Government (2020)

<sup>187</sup>. Royal College of Psychiatrists (2020)

<sup>188</sup>. Cassidy et al (2020); Pellicano and Stears (2020)



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## Concluding thoughts

Our report highlights the diversity of experience amongst autistic people in the UK, and, although statements applicable to all autistic people during the pandemic are not possible, some common themes do emerge. These include the consequences of poor communication from government, highly variable responses from schools, issues with grocery shopping, impacts on mental health, and the effects of the pandemic on health and social care services.

We should emphasise the limitations of current evidence. This includes the more pervasive difficulty of gauging the experiences of autistic people who cannot speak or have severe care needs, or who for whatever reasons, do not have a voice in the discussions that inform responses to the COVID-19 pandemic.



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