

The impact of the COVID-19 pandemic on autistic adults – a survey

Conor James Davidson, Keri Lodge and Alwyn Kam

Abstract

Purpose – To date there has been limited research on the impact of the COVID-19 pandemic on autistic people. This study aims to present the results of a survey of autistic people (n = 51) conducted by a UK specialist autism team.

Design/methodology/approach – A cross-sectional online survey.

Findings – A total of 72% respondents reported either some or significant deterioration in mental health during the pandemic. The issues that caused most negative impact were uncertainty over what will happen next and disruption of normal routine. Respondents reported a variety of coping strategies to help them through the pandemic.

Originality/value – To date there has been little research looking specifically at the impact of the COVID-19 pandemic on autistic people. This paper adds weight to the evidence that the pandemic has had a particularly severe impact on autistic adults and includes useful information on potential coping strategies for this population.

Keywords Autism, Health, Adults

Paper type Research paper

Conor James Davidson and Keri Lodge are both based at the Leeds Autism Diagnostic Service, Leeds & York Partnership Foundation Trust, York, UK. Alwyn Kam is based at the Leeds Autism Diagnostic Service, Leeds and York Partnership NHS Trust, Leeds, UK.

Introduction

In March 2020, the World Health Organization announced that the coronavirus disease 2019 (COVID-19) was pandemic ([World Health Organization, 2020](#)). Countries were advised to implement measures including social distancing, closures of schools and universities, home working and avoidance of travel ([Prime Minister's Office, 10 Downing Street, 2020](#)). It is acknowledged that the potential impacts of the COVID-19 pandemic and associated lockdown measures on the mental health and well-being of people in the general population may be extensive, with “[...] a parallel epidemic of fear, anxiety and depression” ([Yao et al., 2020](#)), and an increased demand for mental health services. People with a mental health condition may be at risk of worsening or relapse during the pandemic because of their high susceptibility to stress ([Campion et al., 2020](#)). People with autism may be particularly at risk as a consequence of a higher prevalence of co-occurring mental health conditions, such as anxiety ([Eshraghi et al., 2020](#)). Core features of autism, including an insistence on sameness, inflexible adherence to routines and ritualised patterns of behaviour ([American Psychiatric Association, 2013](#)) mean that coping with complex changes and unpredictability associated with the pandemic may further exacerbate this risk. Mental health services have also had to reconfigure how services are delivered. In the UK, specialist autism diagnostic services have rapidly moved from face-to-face contact with service users to remote working, including the use of video calls. The impact of these changes on autistic people being able to access the support they need is unknown. Understanding how autistic people are experiencing the pandemic, and the factors helping them find effective ways to cope, is important to inform health and social care services responses ([Holmes et al., 2020](#))

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Research into the pandemic experiences of people with autism is scarce. One recent study (Colizzi *et al.*, 2020) investigated the impact of the pandemic on the impact of autistic children and young people in Italy using an online survey of parents and guardians. The survey comprised 40 questions and aimed to evaluate the impact of the pandemic on well-being and to identify what respondents felt they needed in order to manage. A total of 527 parents and guardians of individuals with autism completed the survey. They reported “behaviour problems” in the autistic children and young people they cared for were more intense (35.5%) and more frequent (41.5%) during quarantine. In particular, survey respondents reported difficulties managing their child’s free time (78.1%) and managing structured activities (75.7%). Multiple logistic regression of factors predicting a negative impact of the pandemic on well-being suggested that individuals with pre-existing behaviour problems were 2.16 times more likely to demonstrate more intense behaviour problems, compared to those without pre-existing behavioural difficulties ($p < 0.001$, 95% CI 1.418–3.291). As a consequence of these behaviour problems, parents and guardians needed an emergency contact with the child’s neuropsychiatrist in 19.1% of cases, and 1.5% of cases required review in Accident and Emergency.

Respondents in Colizzi *et al.*’s study were also invited by means of an open response question to identify what could help them cope with the ongoing pandemic. A total of 406 respondents (77%) reported at least one need. In-home healthcare support was the most frequently reported need (29.9%). Although this survey provides an insight into the impact of the pandemic on autistic individuals, it investigated the perspective of those providing care to autistic individuals, rather than from autistic individuals themselves, and did not focus on autistic adults.

Similarly, at the time of our study, there was little published on the factors which help autistic people to cope with the pandemic. Narzisi (2020) published an editorial aiming to provide tips to help parents and care-givers of young children with autism to cope with lockdown during the pandemic. These tips included providing an explanation of COVID-19; structuring activities of daily life, for example, assigning particular activities to certain rooms; planning activities which allow parents to share their child’s special interests; establishing rules on computer/internet use; allowing time for “spare time”; and weekly online consultations between parents and their child’s therapist. The evidence base for these tips is unclear, and it would appear that the advice is written from the perspective of a clinician in Italy, rather than experts by experience. In addition, the advice is aimed at young children, and to our knowledge, there is no similar published advice aimed at adults.

The impact of the COVID-19 pandemic on the well-being of autistic adults therefore remains largely unknown. This study aimed to address this gap in knowledge by investigating the impact of the COVID-19 pandemic on autistic people through an online survey of individuals diagnosed with autism by the Leeds Autism Diagnostic Service, in Leeds, UK. A second aim was to identify self-reported coping strategies. Our third aim was to evaluate attitudes towards the use of video call appointments.

Methods

Study design

To obtain data in a relatively quick timeframe, a cross-sectional study using a self-report survey was used to gather data on the impact of the ongoing COVID-19 pandemic on autistic people in Leeds.

The survey questions were developed by Leeds Autism Diagnostic Service clinicians, with input from autistic people in our virtual Service User Reference Group and our third sector partner organisation Leeds Autism Advocacy, Information, Mentoring (AIM).

Given the restrictions on face to face contact arising from the pandemic lockdown, the questionnaire was hosted online on the surveymonkey platform and was accessed via a hyperlink.

Approval for the survey was granted by Leeds & York Partnership NHS Trust Research & Development department. During this consultation, we were advised that formal research ethics committee approval was not required because patients had given prior consent to be contacted by the Leeds Autism Diagnostic Service by email. The survey was carried out between 22 May and 15 June 2020.

Survey questions

The survey was deliberately kept relatively short to encourage participation and completion to finish. The questions covered four areas: Impact of different aspects of the pandemic, overall impact on mental health, attitude to remote (video call) assessments, and positive coping strategies. There was also a final free text question for any other comments.

The items for the first question (on the impact of different aspects of the pandemic) were selected on the basis of our clinicians' observations, feedback from service users and other specialist autism teams, and a rapid review of the relevant literature. A recent paper by Sarah Cassidy and others ([Cassidy *et al.*, 2020](#)) was particularly helpful in this regard: it described a round-table discussion on autism and the COVID-19 pandemic by a panel of international experts. The issues of greatest concern included: dealing with uncertainty, changes of routine, loss of normal coping mechanisms, increased social isolation, social distancing, job instability, encroaching government control, worsening mental and physical health, and rationing of health services. This helped to inform the final list of 13 items used in the current survey.

Participants were asked to rate the impact of each item on a five-point scale as follows:

1. This has been positive for me.
2. This hasn't affected me.
3. This has had a negative effect on me (e.g., caused an increase in anxiety levels).
4. This has had a very negative effect on me (e.g., caused very high anxiety or low mood).
5. This has had a very serious negative effect on me (e.g., triggered suicidal thoughts).

The scale was restricted to five gradations and the examples of negative effects were included following feedback from autistic people that the response options should be as specific as possible. An option of "positive impact" was included in recognition of anecdotal reports that some autistic people have found certain aspects of the pandemic lockdown beneficial (e.g. social distancing). The scale was weighted towards negative impacts (three possible negative choices vs one positive choice) because the evidence we reviewed suggested that the overall impact of the pandemic has been net negative for both the general population and the autistic population.

The survey was anonymous. To maintain brevity, demographic questions were not included.

The survey questionnaire included a telephone number and email address if the participant wished to contact us for any reason. It also included a link to a new West Yorkshire-wide service offering support to neurodiverse people during the pandemic.

Participants

The survey questionnaire link was emailed to all patients on the Leeds Autism Diagnostic Service caseload who had received a positive autism diagnosis and were waiting for a follow-up appointment. In total this was 48 people. All were aged over 18. As the Leeds Autism Diagnostic Service is an all-IQ service, some respondents may have had a

comorbid learning disability but this data was not specifically collected in the survey. A total of 35 responses were received.

Given that the population of eligible survey participants was relatively small, steps were taken to identify further participants using social media. On 8 June 2020, the survey link was tweeted by the lead author and the Leeds Autism AIM twitter account. It was specified in the tweets that the survey was for autistic people only. The first page of the questionnaire itself asked participants to confirm they had a diagnosis of autism before proceeding. A total of 16 responses were thereby received.

The final sample comprised 51 respondents.

Analysis

The survey generated quantitative data and qualitative data.

Quantitative data was analysed using descriptive statistics to show the proportion of participants giving particular responses to questions.

The items in question 1 were also ranked using a weighted average score to illustrate which aspects of the pandemic have had the greatest impact.

Qualitative data generated from free text responses in the survey was analysed by each of the three authors independently examining the data to identify common themes. Final themes were agreed by consensus discussion.

Results

There was a total of 51 respondents. Leeds Autism Diagnostic Service sent 48 survey invitations via email to those with a recently established diagnosis of autism and this resulted in 35 responses. Thus the response rate from confirmed service users from the Leeds Autism Diagnostic service was 72%. This is a high response rate for surveys of this type (Baruch and Holtom, 2008), perhaps reflecting the high salience the COVID-19 pandemic has for people at this time. A further 16 responses were received as a result of a Twitter invitation, constituting 31% of the total responses. The sample sizes of the two collection methods were too small to allow for statistical comparison between the subgroups.

Survey question completion rates

The questions in the survey were not compulsory, so a respondent need not answer a question if they wished. However, questions requesting a selection choice attracted a high completion rate (Table 1). The mean completion rate for these questions was 97.9% ($s = 2.1\%$).

The remaining enquiry with Question 4: "We would also like to hear about any positive coping strategies that you are using to maintain your health and wellbeing during the pandemic" invited only free text comments as a response. This attracted 28 comments.

Each question and aspect area, apart from Question 2, also had the option to leave a free-text comment. Additional information from these comments was also examined and provided some context to the answers given.

Impact of different aspects of the pandemic

Question 1 consisted of a subset of questions covering 13 different areas and invited responses with a choice of 5 options as described earlier in the Methods section. A scale was devised to quantify the overall impact. This comprised of awarding a weighting of -2 for "positive", 0 for "neutral", 1 for "negative", 2 for "very negative" and 3 for "seriously negative" responses. Each "positive" response was weighted at 2 because there was only

one possible positive response versus three possible gradations of negative response. Each item was then ranked in order of overall impact based on its total score (Figure 1).

These results show that the areas that autistic people surveyed found most negatively impactful were “Uncertainty over what will happen next” and “Changes to normal routine”. These also attracted the highest “seriously negative” scores. The item “Uncertainty over what will happen next” has the highest negative scores of all three negative severities. Some examples of comments in relation to these areas are shown in Box 1.

Box 1: Examples of comments received in most highly impacted areas

Uncertainty over what will happen next

“Uncertainty and not being in control really makes me anxious”. (Rated: Negative).

“Not knowing whether there will be a second wave and what I can and cannot do is problematic. The same goes for other people’s actions as the lockdown is eased”. (Rated: Very negative).

Changes to normal routine “I found that initially the disruption to my routine was terrible, and it took me a couple of weeks to adjust. Now, though, I’ve managed to get into a routine over the last eight weeks or so, and it’s been great”. (Rated: neutral).

“This has had a big impact, I finding hard to work out the new rules and just want normal back” (Rated: Seriously negative).

The least negative areas were “Having to homeschool children”, “Having to spend more time with household members” and “Problems with police”. “Having to homeschool children” and “Problems with police” had a high rate of neutral responses (83% and 86%, respectively).

It is noteworthy that the items “Having to spend more time with household members” and “social distancing” attracted a particularly high proportion of “positive” responses.

Examples of comments received in these areas are shown in Box 2.

Table 1 Completion rates of survey components

<i>Question</i>	<i>No. of responses</i>
1. Impact of different aspects of the pandemic:	
Uncertainty over what will happen next	51 (100%)
Changes to normal routine	51 (100%)
Not being able to access normal activities	50 (98%)
Readjusting to normal life after the pandemic ends	50 (98%)
Catching the virus/fear of catching the virus	50 (98%)
Difficulty getting supplies	50 (98%)
Reduced support	50 (98%)
Problems accessing healthcare	49 (96%)
Not being able to go to work or place of education	49 (96%)
Social distancing	50 (98%)
Problems with police	50 (98%)
Having to spend more time with household members	51 (100%)
Having to homeschool children	47 (92%)
Overall, how has your mental health been affected by the pandemic?	51 (100%)
3. What do you think of having an autism assessment or follow-up appointment by videocall?	49 (96%)

Box 2: Examples of comments received in least impacted areas (along with the corresponding rating provided by the respondent for that item)

Having to homeschool children “I have no children” (Rated: Neutral).

“This has been the main source of stress, but the school have been very good in providing learning materials, and we soon found a routine that worked. One of my daughters is also autistic, so I think she has benefitted from the home schooling routine”. (Rated: Negative).

Having to spend more time with household members “I have enjoyed spending more time with my wife and kids”. (Rated: Positive).

“On my own” (Rated: Neutral).

“It is VERY challenging all of us being in the same space all the time. It is noisy, messy, chaotic. I have zero time to self-regulate and am existing in a constant state of overstimulation which is causing me to be irritable, angry, upset and unable to function” (Rated: Seriously negative).

Problems with police

“I don’t go outside anymore so, no more problems with police” (Rated: Positive).

“I very rarely go outside and I don’t live independently so this is not an issue for me. Speaking about this does, however, make me scared that it will happen”. (Rated: Neutral).

Social distancing

“I have enjoyed the solitude of being alone” (Rated: Positive).

“I miss being with people I am close to”. (Rated: Neutral).

“Although being separated from the people I care about has been hard I do prefer distancing from people when in public as this helps reduce my social anxiety knowing people can’t touch me and are less likely to speak to me” (Rated: Very negative).

Effect on mental health of the pandemic

Participants were asked to select one option in response to the question “Overall, how has your mental health been affected by the pandemic?” with 5 options ranging from “a lot better” to “a lot worse” (Figure 2).

In general terms, 72% of the responders felt their mental health was worse, 14% felt no different and 14% felt better as a result of the pandemic.

Attitude to remote (video call) assessments

Figure 3 shows the results of the question about video call assessment. A total of 71% would agree to a video call clinical appointment, with 16% actually preferring a video call over a face-to-face encounter. However, the remaining 29% would rather choose to wait for the availability of face-to-face appointments after the lockdown. We plan to report on these results in more detail in a separate paper.

Positive coping strategies

Question 4 was a single free-text prompt asking the following: “We would also like to hear about any positive coping strategies that you are using to maintain your health and well-

being during the pandemic". There were no standard options to select in this question and 28 text comments were received. A range of responses were received, which were grouped into key themes. Table 2 shows the themes, the frequency of responses (total number is more than 28 because many respondents described more than one coping strategy) and representative examples.

Establishing new routines and making plans was a key coping strategy identified by respondents. The methods they used to achieve this included writing daily to do lists, weekly plans and meal plans. For some respondents, their new routines included focusing on existing special interests, for example: "[...] throwing myself into special interests, essentially keeping so busy and suitably stimulated that I don't have enough brain power left free to focus on covid", or developing new ones, for example: "researching and looking after my indoor and outdoor plants".

Another was to keep busy by engaging in chores or leisure activities including reading or listening to podcasts, baking, drawing, crafts, building lego and keeping a diary, for example: "I have started a crochet blanket, this keeps me occupied and stops my mind wandering too much".

Spending time in nature was another key coping strategy, for example: "We like sitting outside in my tiny yard and watching the birds, I've bought a comfy chair and a bird identification book". Another respondent explained: "I have planted lots of seeds and enjoyed seeing them grow. The constancy of the changing seasons and the cycle of nature gives me comfort in uncertain times".

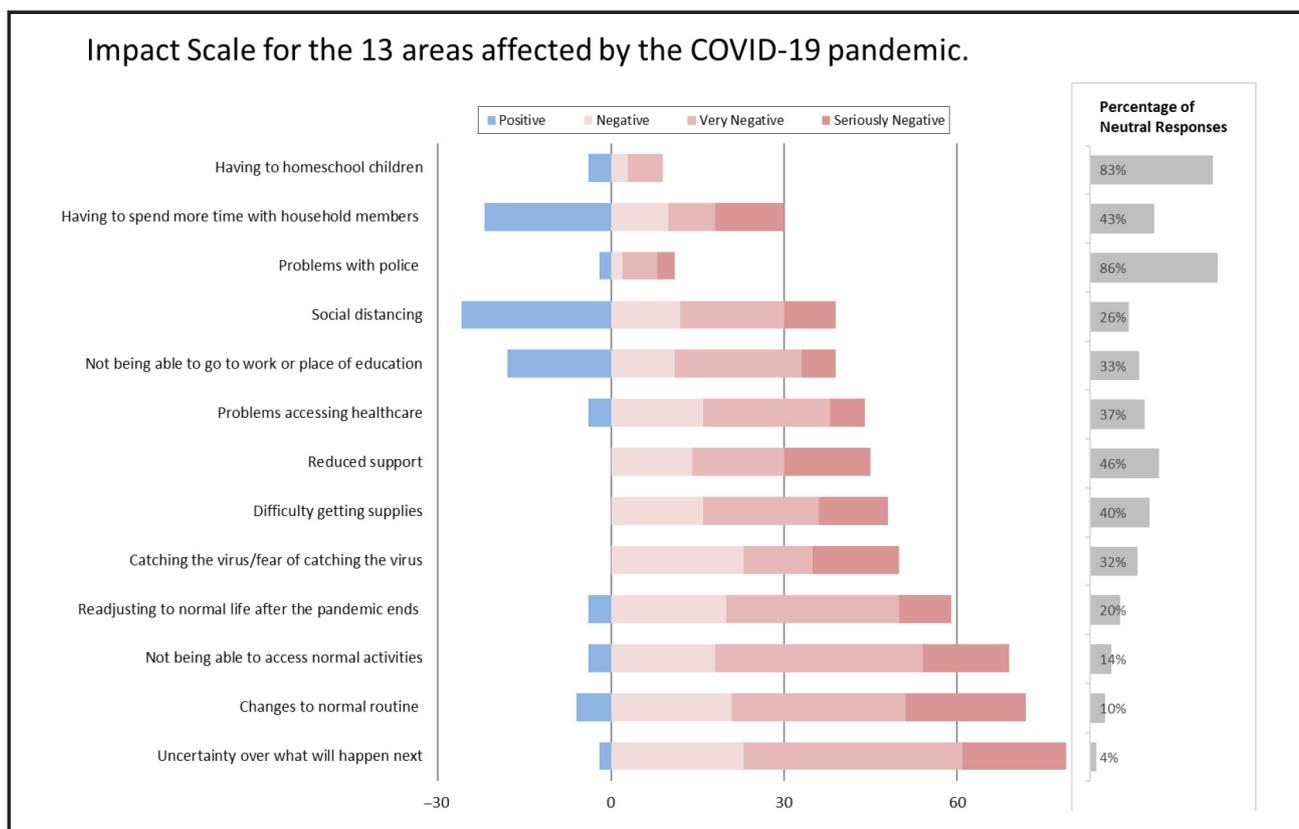
Linked with this, spending time with pets helped others cope, for example: "Taking my dog for a walk, we are exploring different areas where I live, I can't walk far, so I'm limited - but, I've enjoyed finding hidden places, or unoccupied places".

Other respondents reported that other forms of exercise helped them cope: "Running. But it's hard to go out. The less I'm able to go out, the more difficult I find it!"

Table 2 Summary of positive coping strategies suggested by participants in the survey

<i>Theme</i>	<i>No. of responses</i>	<i>Examples</i>
Routines and rituals	11	Using a weekly planner Planning meals Stimming
Leisure activities	11	Crafts Baking Drawing Lego
Social interaction	10	Videocalling friends Social media Writing letters
Relaxation/managing worry	10	Limiting exposure to news Meditation and mindfulness Avoiding sensory stressors
Nature	7	Bird watching Gardening Observing the seasons
Exercise	6	Walking Running Cycling
Work	5	Focusing on work Managing workload
Special interests	3	Focusing more on special interests

Figure 1 Areas ranked by Impact Scale from least negative to most negative, showing scores and proportion of neutral responses



Finding ways to manage worry was a further key coping strategy. Methods used by respondents included yoga, meditation, the Calm App, mood diaries and gratitude journals. One respondent described that stimming helped them: “Stim early and often. Just stim all the time”. Another respondent described how managing sensory stimuli helped them cope: “Avoiding loud noises, too much sun [...]”. Contact with others was another key positive coping strategy, for example, “I’ve been writing letters to people, and I like it when they are happy to receive them (I include photos and small gifts). I’ve also made short videos of my walks and the sound of the trees and birds and river (I’ve called them covideos) and I send these to my friends and mum who are shielding and can’t go out. “Other respondents described using technology such as videocalls and social media helped them keep in touch with family or with other autistic people, which they found helpful.

Conversely, for other respondents, it was disconnecting with others that helped them cope. One respondent explained, “I can finally be at peace, no more being invited to parties or social gatherings. I dread when the pandemic ends”. Another described going outside at less busy times, such as the early morning, helped them cope.

Discussion

This paper is the first in a peer-reviewed journal to our knowledge to present original data on the impact of the COVID-19 pandemic on autistic adults in the UK. A total of 35% of our respondents reported their mental health had got a little worse; 37% a lot worse. For comparison, a very recent survey of autistic people and carers by the UK National Autistic Society published online found

Figure 2 Proportion of responses on the effect of the pandemic on overall mental health

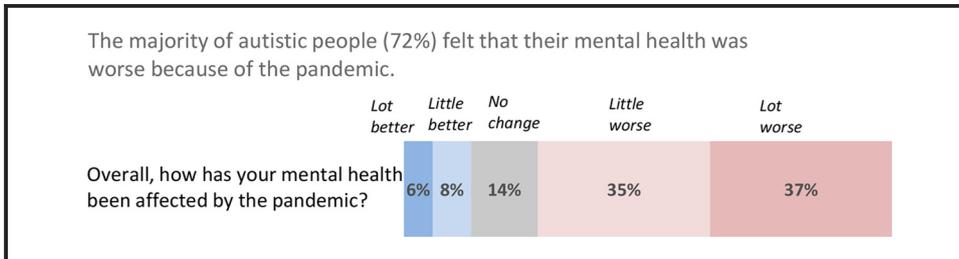
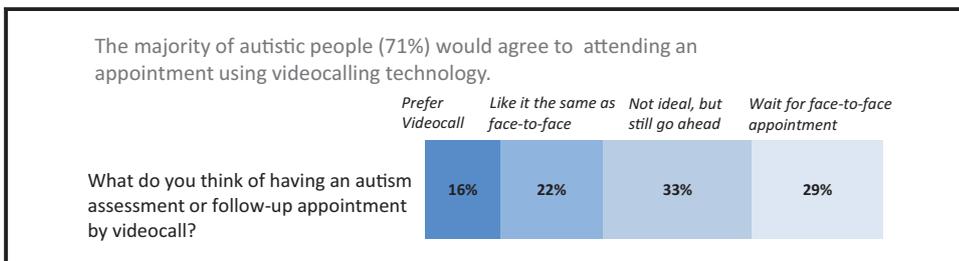


Figure 3 Proportion of responses on the use of videocalling technology for clinical appointments



that 9 out of 10 reported worrying about their mental health during lockdown and 85% reported increased anxiety (National Autistic Society, 2020). Although direct comparisons with general population survey data are difficult because of differing methodologies, Office of National Statistics survey data shows 69% of the UK general population report feeling somewhat or very worried on the effect COVID-19 is having on their life (Office for National Statistics, 2020). The UK Household Longitudinal Study found an increase in mental health problems from 23.4% of respondents pre-pandemic to 37.1% in April 2020 (Daly et al., 2020).

In our opinion it is likely that on average autistic people have experienced greater negative impact from the pandemic than non-autistic people. This is in part because autistic people have higher baseline levels of comorbid mental disorder (Mannion and Leader, 2013) in any case. However, our survey adds to the emerging anecdotal evidence that certain intrinsic features of autism make it more difficult to cope with the momentous socioeconomic upheaval caused by a global pandemic. The two most negatively ranked items in our survey were “uncertainty over what will happen next”, and “changes to normal routine”. Autistic people are more prone to anxiety caused by Intolerance of Uncertainty (South and Rodgers, 2017). A number of our respondents made reference to uncertainty - for example: inconsistent messaging on lockdown rules, whether a “second wave” will emerge, and what the “new normal” will look like. The diagnostic criteria for Autistic Spectrum Disorder include “insistence on sameness” and “inflexible adherence to routines” (American Psychiatric Association, 2013). In the pandemic, normal activities and routines have been disrupted by lockdown and social distancing requirements; it would be expected that autistic people will find such disruption particularly challenging.

Two items in our survey had a striking proportion of respondents reporting a positive impact: “social distancing”, and “having to spend more time with family members”. Free text responses indicated that some autistic people prefer to be solitary, and value the reduced likelihood of being approached or touched in public. We may speculate that new social norms during the pandemic such as non-contact greetings, restricted mass gatherings, and fewer daily social interactions are

on balance favourable to the autistic population. Spending more time at home with family members can be positive or negative depending on personal circumstances – the lockdown is more bearable with a large house, garden, and mutually supportive family relationships.

This paper is also, to our knowledge, the first to identify the self-reported coping strategies autistic adults are using to cope with the pandemic. Although COVID-19 may be having a disproportionately negative impact on autistic people, the respondents in our survey demonstrated remarkable resilience and positivity, and disseminating the coping strategies they identified may support other autistic adults, and those involved in their care and support, to find similar ways to cope. Finally, our survey highlighted that video call assessments may be acceptable to autistic people, and this may inform future approaches to the delivery of care to this population given that they may, as a consequence of the core features of autism, which include difficulties with social interaction and communication, find face to face contact challenging.

We acknowledge a number of limitations in our study. First, our sample size was small and we did not collect demographic details, meaning it is unknown whether participants differed significantly from the population from which they were drawn. In addition, our survey did not gather data on comorbidities, such as mental health conditions or the presence of a learning disability, which in themselves may be confounding factors influencing an individual's response to, and ability to cope with, the pandemic. Future studies should gather this demographic information. A second key limitation was our recruitment methods, which result in a risk of selection bias. Leeds Autism Diagnostic Service is an "all-ability" service and sees patients across the full range of intellectual functioning. However, participants recruited from the service's caseload were emailed the survey, which means that people unable to access email or to use this independently may have been excluded. This would likely particularly apply to patients with intellectual disability and those with significant speech and language problems. Additionally, although participants recruited via Twitter were asked at the start of the online survey to confirm they have a diagnosis of autism, we are reliant on participants' self-reports of this diagnosis. A further limitation arises from the use of a five-point scale with three "negative" options, one neutral and one positive. We acknowledge that the scale used was asymmetrical, introducing a risk of bias in responses towards the negative categories, and a risk of confirmation bias, i.e. confirming the pre-existing assumptions of the researchers as a consequence of the design of the scale used. However, we opted for this scale on the basis of clear evidence that the pandemic has had predominantly negative mental health effects for the overall UK population (Pierce *et al.*, 2020). Finally, our analysis relies on descriptive statistics only, as we did not include a non-autistic comparison group. Future research on this topic should ideally include a neurotypical control group to determine whether autistic peoples' response to the pandemic differs significantly from non-autistic. Despite these limitations, our study provides a useful description of how participants are coping with the pandemic at a particular point in time, and provides a useful springboard for further research.

In conclusion, the results of our study indicate that autistic people may be experiencing a particularly negative impact on their mental well-being during the ongoing COVID-19 pandemic, although some have developed positive coping strategies. It is likely that autistic people will continue to experience challenges with adapting to the ongoing uncertainty and changes to their daily life resulting from the pandemic. Our survey highlights the need for secondary mental health services to ensure they are delivering the support needed to autistic people, which may include the ongoing use of remote technologies such as video calls, as well as disseminating the positive coping strategies identified by participants in our survey.

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Corresponding author

Conor Davidson can be contacted at: conor.davidson@nhs.net

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