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“This may be a really good opportunity to make the world a more autism friendly place”: Professionals’ perspectives on the effects of COVID-19 on autistic individuals

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ABSTRACT

Background: The COVID-19 (C-19) pandemic affects everyone. Autistic individuals may be at increased risk of experiencing difficulties coping with the impact of C-19 (e.g. due to unexpected changes to usual activities and routines, and the general sense of uncertainty). This preliminary study gathered the perspectives of health and social care professionals, and researchers, about: (1) vulnerability factors for coping with the pandemic; (2) the impact of the pandemic; (3) service provision during the pandemic; and (4) interventions to support reintegration during and post the pandemic.

Method: We conducted an online survey, comprising Likert-scale and free text responses. Quantitative data were analysed descriptively, and qualitative data thematically.

Results: Thirty-seven participants, working in clinical, education and academic settings with autistic individuals, completed the survey. C-19 had substantially impacted service provision, causing major disruption or loss of services. Thematic analysis indicated six overarching themes: (1) vulnerability factors for coping with C-19 and lockdown; (2) positive and negative impact of lockdown (for autistic individuals, families and professionals); (3) public health response to C-19; (4) service provision during the pandemic; (5) inequalities; and (6) looking to the future.

Conclusions: Professionals, across disciplines and settings, must now work together with autistic individuals and their families, to understand the impact of these extraordinary circumstances and develop ways everyone can be supported more effectively.

1. Introduction

COVID-19 (C-19) has caused a global pandemic. Curbing the spread of C-19 relies on: (1) rapidly identifying positive cases; (2) quarantine of symptomatic or exposed individuals; (3) abrupt enforced closure (lockdown) of non-essential services; (4) shielding of...
high risk individuals; (5) social distancing; and (6) use of personal protection equipment (PPE; World Health Organisation, 2020). Some measures - specifically, social distancing, shielding and lockdown - may be associated with adverse secondary effects; for example, loss of usual activities (e.g. education/occupation, social events), financial and material hardship (e.g. due to redundancy, furloughing of staff, limited access to food; Nicola et al., 2020; Power, Doherty, Pybus, & Pickett, 2020), isolation and loneliness (Jordan, Adab, & Cheng, 2020), onset or exacerbation of mental health conditions (e.g. depression, anxiety; Mazza et al., 2020; Wang et al., 2020), and disruption to service provision (Lancet, 2020).

It is important to understand how C-19, lockdown and social distancing impact particular populations (e.g. specific age groups, clinical populations), as risk/protection factors for disadvantage, physical or mental ill health, or treatment of these, may vary between groups (Hamner, Kivimäki, Gale, & Batty, 2020; Petzold et al., 2020; Serafini et al., 2020; Williamson et al., 2020). Autistic individuals are conceivably at heightened risk of experiencing difficulties coping with the pandemic and resultant measures (Ameis, Lai, Mulsant, & Szatmari, 2020; Colizzi et al., 2020; Pellicano & Stears, 2020). Loss of usual routines and activities may prove anxiety-provoking (Gilloitt & Standen, 2007; Kerns et al., 2014). Autistic students may struggle with abrupt changes to course delivery and mentorship programmes, due to school and college closures (Sahu, 2020; Viner et al., 2020). Many autistic individuals require support (e.g. from family or (non)statutory services; den Houting, 2020); yet services may have paused temporarily, or practical obstacles may impede input (e.g. lack of transport, need for shielding) (White et al., 2020). Background health may also increase risk, as autistic individuals experience disproportionately high rates of obesity (Zheng et al., 2017), and physical (Croen et al., 2015) and mental health conditions (Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2019).

Recent editorials and position papers highlight clinicians’ and researchers’ concerns about the experience of C-19 and lockdown by autistic individuals, with and without an intellectual disability (ID). Engaging in education, activities and health interventions from home might suit some; yet conversely, coping with unpredictable changes in routine, alongside indefinite uncertainty and less support, might exacerbate inequalities and poor mental health (Ameis et al., 2020; Cassidy et al., 2020; den Houting, 2020; Pellicano & Stears, 2020; Tromans et al., 2020).

A handful of studies have investigated C-19 and autism, primarily from the perspectives of caregivers, with very few recruiting autistic individuals or professionals. Studies have comprised online surveys (Bal et al., 2021; Colizzi et al., 2020; Oomen, Nijhof, & Wiersema, 2021; Manning, Billian, Matson, Allen, & Soares, 2020; Mutter, Doenys, & Aslan Genc, 2020; Nonweiler, Ratray, Baulcomb, Happé, & Absoud, 2020; White et al., 2020), telephone interviews (Neece, McIntyre, & Fenning, 2020), retrospective analysis of records (Pollard, LeBlanc, Griffin, & Baker, 2020), and descriptions and preliminary analyses of adaptations to clinical work, such as conducting diagnostic assessments and delivering care and interventions remotely (Kalvin et al., 2020; Sivaraman, Vireus-Ortega, & Roeyers, 2020; Wagner et al., 2020). Participants have been recruited from clinical services, research cohorts and non-clinical (community) settings.

Key findings across cross-sectional studies that have obtained data from caregivers indicate that: (1) disruption to, or loss of, health or support services has occurred commonly; (2) education and schooling has also been disrupted; (3) coping with uncertainty and unexpected changes to everyday activities, and a lack of routine, has proven difficult for many; (4) it has not been straightforward to identify pandemic compatible activities (5) some families are experiencing financial concerns; (6) C-19 and lockdown has adversely affected caregiver stress / mental health; and (7) the current situation may have contributed to emotional and behavioural disturbance in autistic individuals (see Colizzi et al., 2020; Manning et al., 2020; Mutter et al., 2020; Neece et al., 2020; Nonweiler et al., 2020; Pollard et al., 2020; White et al., 2020).

One study by Oomen et al. (2021) has garnered perspectives about the pandemic from autistic and non-autistic adults. Both participant groups reported experiencing stress, anxiety, worry and depression as a result of the pandemic, with autistic individuals endorsing higher rates and levels of affective symptoms. Some autistic individuals may feel more ‘comfortable’ with conducting clinical work online, yet they also noted considerations and pitfalls with this (e.g. problems with IT, that the environment patients were in for the appointments were not always conducive to assessment). Additionally, in a commentary, Kalvin et al. (2020) have identified some challenges to providing cognitive behaviour therapy (CBT) remotely, based on their practice; for example, autistic individuals may be distracted while at home and some techniques may not be feasible (e.g. use of visual aids). Conversely, they also noted some advantages to this approach, including an improvement in attendance and flexibility in appointment scheduling, and that autistic individuals may feel more ‘comfortable’ being seen at home.
It is clear that C-19 and the resultant measures have had an enormous impact on all of us. The evidence to date suggests that some autistic individuals may be at increased risk of struggling with the impact of this. They are also very likely to have experienced disruption to service provision. Seeking to complement the quantitative survey methods of existing research outlined above, this preliminary mixed-methods study (incorporating quantitative and thematic analyses), sought to explore the perspectives of health and social care professionals\(^2\) and researchers working with autistic individuals, about: (1) vulnerability factors for coping with the pandemic; (2) the impact of the pandemic; (3) service provision during the pandemic; and (4) interventions to support reintegration during and post-pandemic. We sought the views of clinicians and researchers to address these aims as they have a working knowledge of service provision before C-19, and are well-placed to offer insights into how services can be adapted currently and prospectively. We also considered that professionals and researchers may offer a different perspective that has only minimally been captured in studies to date (e.g. Pollard et al., 2020; Wagner et al., 2020), and that their perspectives might differ from caregivers, for example, given that they may work with other populations and age groups.

2. Methods

This was a cross-sectional study, conducted via an online (Qualtrics) survey.

2.1. Participants and procedure

The study was open to health and social care professionals, and researchers, working with autistic individuals in England. We opted to include researchers in this sample as many engage in direct work with autistic individuals and their families, and some of this is treatment research. Participants were recruited via: (1) gatekeepers at health, social care and academic organisations; (2) the Autistica Network (a UK network of autistic individuals, family members and professionals, who have consented to be contacted about research); (3) social media; and (4) word of mouth.

The study attained ethical approvals (MRA-19/20-18339). Participants responded anonymously, but could opt in to a prize draw, for the chance to win one of five £25 gift vouchers. The recruitment period was 28 April to 31 May 2020. During this time in England, lockdown was in place; government guidelines stipulated individuals could only leave home for essential provisions, medical care and one hour of exercise daily (HM Government 2020).

2.2. Participant characteristics

Thirty-seven participants, working across settings, completed the survey: six psychologists, four speech and language therapists, three occupational therapists, three nurses, two psychological therapists, one medical doctor, 12 unqualified staff (e.g. assistant psychologists, support workers) and eight researchers. Approximately half of participants worked with adults, 43% with young people and 8% with individuals across the lifespan. All participants indicated working primarily with autistic individuals; 12 had less than four years experience, seven had between five and nine years experience, and 18 had 10+ years experience.

2.3. Survey development

The survey (see Supplementary File 1) developed from conversations with autistic adults, family members of autistic children and clinical-academics. Two autistic adults reviewed the survey format and content. This included demographic questions about professionals’ roles and work experience (e.g. clarifying professional discipline of origin if applicable, and what setting participants worked in), qualitative questions (e.g. “what have been the biggest challenges for you in relation to caring for or working with autistic people”, “how might you do things differently in the future as a result of this experience”, “please use the space below to describe your experiences, and that of your clients/participants, with telehealth”, and quantitative questions with items rated on a five-point Likert scale, ranging from ‘not at all’ to ‘quite a lot’ (e.g. a list of potential contributory factors for stress experienced by autistic clients/participants; see Fig. 1).

2.4. Data analysis and coding

Data pertaining to demographic characteristics, and ranking of factors potentially exacerbating stress at this time, were summarised descriptively. Qualitative data were analysed thematically. Thematic analysis comprises six stages: (1) becoming familiar with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) naming themes; and (6) summarising the data (see Braun & Clarke, 2006, p.87). All open ended (free text) responses were collated in one transcript. This was reviewed by DS several times. Initial codes were highlighted within the text. These were grouped into categories, then organised consecutively, with headings (labels) assigned to themes and sub-themes. The transcript was reviewed again, to establish if any codes or categories were not adequately described by tentative themes. Table 1 and Supplementary file 2 outline the coding process.

To enhance rigour, a proportion of qualitative data was reviewed by DM and SC, who were allocated consecutive and overlapping

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\(^2\) Social care professionals tend to work with individuals in the community, providing practical and social support, rather than healthcare interventions.
transcript pages (pages 1–4, 3–6, 16–20 and 18–22). These pages were chosen as they reflected responses to questions about current challenges/difficulties (pages 1–6), and teletherapy and ways of improving services/enhancing reintegration (pages 16–22). Altogether, 10% of the data were evaluated by three researchers, and 20% by two researchers, in line with suggested guidelines for reliability coding of qualitative data (Syed & Nelson, 2015). Annotated transcripts were compared; final themes and sub-themes were discussed. As is requisite for qualitative research, we embedded reflexivity within the study process (Berger, 2015), for example, acknowledging: (1) similarities and differences in our opinions about, and means of, coping with the pandemic; (2) ways in which our professional backgrounds (clinical vs. non-clinical) and work contexts (academia vs. health) might influence our ideas about C-19 and autism; and (3) how previous research experience might shape our approach to the dataset.

Table 1
Overview of themes and subthemes.

| Theme                                           | Definition of theme                                                                 | Subtheme                                      | No. of coded text segments |
|-------------------------------------------------|--------------------------------------------------------------------------------------|-----------------------------------------------|----------------------------|
| Vulnerability factors for coping with C-19     | Factors associated with autism, that may impact capacity for coping with the onset of the pandemic and resultant measures put in place | Social communication impairments              | 14                         |
|                                                 |                                                                                      | Difficulties tolerating uncertainty           | 27                         |
|                                                 |                                                                                      | and coping with change                        | 22                         |
|                                                 |                                                                                      | Neuropsychological traits                     | 66                         |
|                                                 |                                                                                      | Impact on autistic individuals                 | 24                         |
| Positive and negative impact of C-19 lockdown  | The multiple direct and indirect ways in which C-19 lockdown has impacted key stakeholders | Impact on autistic individuals’ families       | 37                         |
|                                                 |                                                                                      | Information dissemination                      | 37                         |
|                                                 |                                                                                      | Social distancing measures                    | 18                         |
|                                                 |                                                                                      | PPE                                            | 17                         |
|                                                 |                                                                                      | Infrastructure and staffing                   | 41                         |
| Public health response to C-19                 | Informational and instructive reactive and proactive steps taken by the government to manage, curtail and treat C-19 | An evidence-based vs clinically pragmatic approach | 22                         |
| Service provision during the pandemic          | The design, delivery and evaluation of clinical service provision during the pandemic | Advantages and constraints of telehealth       | 95                         |
| Inequalities                                    | General and specific areas of potential inequality and discrimination, arising in the context of the pandemic | A change in ethos                             | 30                         |
| Looking to the future                          | The theoretical, empirical, systemic and practical implications for improving service provision for autistic individuals, as a consequence of C-19 | Policy reform                                 | 28                         |
|                                                 |                                                                                      | Research implications                          | 11                         |
|                                                 |                                                                                      | Reshaping service provision                   | 51                         |
|                                                 |                                                                                      | Living in the ‘new normal’                    | 113                        |
3. Results

3.1. Thematic analysis

Qualitative analysis of open-field responses indicated there were six overarching themes: (1) vulnerability factors for coping with C-19 and lockdown; (2) positive and negative impact of lockdown (for autistic individuals, their families and professionals); (3) public health response to C-19; (4) service provision during the pandemic; (5) inequalities; and (6) looking to the future (see Table 1).

3.1.1. Vulnerability factors for coping with C-19 and lockdown

The first theme encapsulated vulnerability factors for coping with C-19 and lockdown, with three sub-themes.

3.1.1.1. Social communication impairments. Some participants considered autistic individuals to have struggled with verbalising their thoughts due to expressive or receptive communication difficulties, or if they “haven’t had helpful experiences [of seeking support] in the past”. Communicating by telephone/online was deemed challenging, as professionals felt that some autistic individuals “really value face to face interactions”. Bi-directionally, one participant noted “some GPs [General Practitioners] may struggle to understand or communicate clearly with autistic people”.

3.1.1.2. Difficulties tolerating uncertainty and coping with change. Participants deemed some autistic individuals to feel very anxious due to “the uncertainty [of the situation] and change to routines”; compounded by the problem of “not being able to plan or give a time when services will be open”. Participants consistently mentioned autistic individuals’ feeling “upset, anger and anxiety [about] not being able to do the normal day to day routines they are used to”. Coping with “removal of usual coping strategies” (i.e. due to lockdown), and problems identifying alternatives, was viewed as especially difficult.

3.1.1.3. Neuropsychological traits. Participants perceived particular neuropsychological traits (cognitive skills), commonly associated with autism, to increase vulnerability around making sense of, and coping with, the pandemic. Autistic individuals were said to prefer “a set of rules in black and white”. Constant changes regarding measures in place had seemed to prove confusing. Participants reported that some autistic individuals appeared to have a “problem when others [were] seen flouting the rules”, potentially exacerbated by a tendency for “all or nothing” thinking and overgeneralising. Consequently, they may experience difficulty weigh up exceptions to the rules, such as balancing “the risks from inactivity and general loss of life vs. risk from potentially contracting the virus”.

Additionally, based on the quantitative data, Fig. 1 summarises participants’ views about factors they deemed might exacerbate autistic individuals’ stress during lockdown. Difficulties coping with change (a core autism symptom), neurocognitive impairments (notably, difficulties tolerating uncertainty and generating adaptive strategies), executive functioning impairments, poor emotion recognition and regulation skills and co-occurring mental health conditions reportedly elevated stress. Participants proposed two additional vulnerability factors: (1) stress or unpredictability at home; and (2) delayed assessment and treatment of health needs.

3.1.2. Positive and negative impact of lockdown

The perceived positive and negative impact of C-19 lockdown was the second theme, with three sub-themes identified.

3.1.2.1. Impact on autistic individuals. Lockdown was deemed to have impacted on autistic individuals’ education, social lives, activities and health.

Participants stated that for some autistic individuals, abrupt changes to education had been unexpectedly beneficial; for example, “not going to school [was] much better for their mental health”, resulting in “less anxiety managing their own school work”. One participant remarked, “the initial transition from school to home-schooling [had been] difficult, but... [many] have preferred this way of working”. Schooling in residential homes instead of classrooms was described as useful as students were “learning skills directly where they will be used”. Yet, participants considered some autistic individuals to have found studying at home problematic. This had, for instance, resulted in loss of “specialist intervention preschool programmes” and student support. School routine changes were viewed as having been unsettling. Some autistic university students had appeared “more inhibited and less willing/able to share anxieties and concerns that need sensitive supportive responses”. Moreover, “high levels of uncertainty impact[ed] on productivity and engagement, and some students [with] strict study routines [had been] unable to adapt to working at home with the additional interruptions, noise and distractions”.

Some participants reported that autistic individuals they worked with appeared to feel “happy ... a sense of relief” about social distancing. One participant noted “autistic people I’ve worked with have really enjoyed not having the pressure to socialise”. Another said this provided autistic individuals with “a much needed break from having to appear ‘normal’ and a rest from having to do this day in day out at work”. Yet, lockdown also meant delays in them working towards socially-oriented goals, and difficulties meeting with family/friends as they would wish.

Some autistic individuals were reported to have found lockdown useful, as they could more easily choose “their day to day routines around food, what they wear and personal hobbies”. Others were said to have experienced difficulty keeping to “a structured routine ... [doing] activities of daily living and [filling] their daily routines with meaningful activities”, without anchors (e.g. school). Identifying pandemic compatible activities could be taxing. Participants described some concerns that some autistic individuals would not “keep up with the progress they have made, and [that they could] regress due to being unable to leave the house/participate in their usual
social activities”.

Increased “problems managing physical health conditions” were identified. Additionally, uncertain times were said to have “given rise to children’s anxiety levels, [problems with] self confidence and self-esteem”. Lockdown was considered to have serious ramifications for autistic individuals’ mental health now and post-lockdown/pandemic, so poor health provision at the time of the study, was alarming.

3.1.2.2. Impact on autistic individuals’ families. Autistic individuals’ families were also described as having been impacted by lockdown. Families’ “resilience” was highlighted; they were doing the best they could to cope and problem-solve in a difficult situation, while performing many roles (e.g. parent, teacher, co-therapist). Yet, the pandemic appeared acutely challenging for some families, due to stress, an inability “to provide a safe and predictable home life during uncertainty”, and limited support. Even when support was offered (e.g. teletherapy), “it was not always possible for parents to access a private space to talk about their children for a good length of time”.

3.1.2.3. Impact on professionals. Some participants had been affected by the current situation; personally and professionally. The current context impacted emotional well-being, resulting in the need to “proactively [manage] and [contain] feelings of anxiety around change, unpredictability”, and concentrate on “well-being and emotional regulation and sensory needs”. Some participants were “recovering from flu like symptoms from virus presumed to be C-19”. They were also juggling work: life commitments, and coping with reduced in person social contact.

Uncertainty about jobs, and how to adapt these for remote working, was mentioned. Some redeployments had resulted in a “skeleton service for our [autism-specific] service during this time, so it was hard to know whether their [clients’] needs would be met”. Another participant noted it had been “difficult to keep an oversight of my autistic community caseload”. Remote working resulted in participants “missing face to face contact with colleagues/clients”. Lockdown was described as “forcing us all to use new ways of doing our work”, so becoming upskilled rapidly was pressing (e.g. in using online technologies). However, participants identified “we need to think carefully about how much and the type of work we continue to do at home, especially [when] delivering therapeutic interventions. As the boundaries between home and work life are blurred, this may have unintentional consequences for the mental health of health and social care professionals”.

3.1.3. Public health response to C-19

The third theme pertained to the public health response to C-19, with three sub-themes.

3.1.3.1. Information dissemination. Participants outlined pitfalls with the process and content of C-19-related information dissemination to autistic individuals and their families. These included information overload, “a lack of accessible information” (about C-19 and broader issues), “conflicting messages that come out through the media” and “frequent changes in legislation”, resulting in ambiguity. Participants also noted that there had been a “lack of clinical information at the outset to support people with autism with comorbidities” (i.e. professionals did not have sufficient information available to guide practice).

3.1.3.2. Social distancing measures. Participants affirmed that some autistic individuals seemed “quite happy [with] reduced social contact”. Conversely, others - with and without an ID – were said to find these measures problematic. One participant, for example, outlined that a client she supported “likes to go up and shake hands of people he meets, including complete strangers … Staff are often having to use themselves to block this from happening, resulting in challenging behaviour”.

3.1.3.3. PPE. There was “a lack of, and inconsistent use of PPE” in some settings. Participants thought PPE was important, and that “staff should have been prepared to manage the anxieties of autistic people around PPE before introducing it and not after”. They were concerned autistic individuals might struggle to understand and tolerate others wearing this, or require adaptations and “thoughtfulness about the type of face coverings that can be used”. “Significant difficulties with this [face masks] due to their [autistic individuals] sensory needs” were also noted.

3.1.4. Service provision during the pandemic

The fourth theme focused on services provision. Quantitative data obtained in the study, indicated that participants thought that autistic individuals had experienced disruption to service provision; ten participants (27%) stated that there had been mild disruption, 24 participants (65%) said there had been major disruption and three participants (8%) reported a complete loss of services, supports, or therapies.

There were also three sub-themes from the qualitative data, focusing on service provision during the pandemic.

3.1.4.1. Infrastructure and staffing. Temporary closure of services, “loss of direct appointments”, fragmentation of care pathways and the inability to “give a time [for] when services will be open”, were concerning. NHS bureaucracy could be hard to contend with. There were “frustrations with technology”, as few mechanisms existed for remote working in some settings; “even sending emails is hard work as [the] NHS does not allow emails from certain accounts”. Multi-agency working could be very challenging (e.g. messages unanswered, arranging meetings).

“Staff shortages due to self-isolation, redeployment and reluctance to use agency staff [e.g. to reduce C-19 transmission risk]”
occurred commonly. Day to day, participants were expected to determine “the best and safest way to meet with them [autistic individuals] and do my job”, resulting in the need to “trial, reject and retry a range of different communication methods”. A one size fits all service model had limited utility, with teams needing “to select the different communication methods based on the individual, the relationship and the topic”.

Conversely, a shared “can-do” attitude and proactivity from senior management were considered key, as these “filtered down into the rest of the organisation”. “Regular team check-ins were [seen as] important at the beginning of the pandemic, when information was changing daily and our responses needed to change rapidly”.

3.1.4.3. Advantages and constraints of telehealth. Participants commented on use of, and satisfaction with, telehealth; 14 had never used telehealth, 22 had used this due to C-19 and one person used this before C-19 and continued to do so. When asked about preference, 57 % of participants preferred meeting in person and 43 % had no preference either way.

Teletherapy had “pros and cons”. Participants’ views of teletherapy related to six areas: (1) general considerations; (2) patient-related factors; (3) family-related factors; (4) professional-related factors; (5) treatment considerations; and (6) service-related factors (see Table 2).

Telehealth was construed as potentially efficient (e.g. time- and cost-wise), yet depended on the availability of technology. One participant reported “difficulties with poor internet … and varying degrees of technology literacy in our service staff have led to differing experiences within the team and within our clients”. Telehealth also required substantial concentration, and was described as “intense” and “exhausting”; it could be “hard to switch off”. Overall, participants felt teletherapy was “useful in the circumstances” and “an acceptable alternative”, although many preferred in person working.

Preferences of autistic individuals regarding teletherapy were also reported to vary, with one participant suggesting that “some young people particularly [liked this], if they are used to this interface already”. This was also deemed a minimally anxiety-provoking method of engagement. Conversely, some children and individuals with an ID were said to “find telehealth confusing and daunting”. Moreover, they “did not like the video element and prefer[red] audio only”. Participants described that some autistic individuals had “refused to do online therapy [and] stayed out of vision”, affecting capacity to “read expressions” and build rapport. Some parents/

### Table 2

Considerations associated with using telehealth.

| Considerations | Description |
|----------------|-------------|
| General considerations relevant to autistic individuals, their families and professionals | Can prove efficient (e.g. saves on time and travel) |
| | Reduces costs (e.g. for travel) |
| | Requires IT equipment, software, skills and internet connection |
| | Can be difficult to observe and interpret non-verbal cues |
| | Can feel an intense method of communication |
| | Requires focused and sustained attention |
| | Can be a difficult method of input to understand (e.g. for young children) |
| | Can be anxiety-provoking |
| Patient-related factors | May prefer audio, rather than visual communication |
| | May result in avoidance (e.g. easy to leave the room) |
| | May find it difficult to process information |
| | Unable to use tactile forms of communication |
| Family-related factors | Requires time |
| | Requires privacy |
| | Can result in ‘Zoom fatigue’ |
| Professional-related factors | May lead to a blurring of professional and personal boundaries (if working from home) |
| | Requires a suitably confidential space to work |
| | Minimal evidence base for telehealth in autism |
| Treatment considerations | Difficult to incorporate aspects of standard psychological interventions (e.g. exposure) |
| | May not be able to practice strategies in real world settings |
| | Easier to liaise with internal and external agencies (e.g. multi-agency meetings) |
| | Allows for flexibility in appointment duration and frequency (e.g. shorter, more frequent) |
| Service-related factors | Lack of clear policies and guidance |
| | Lack of IT infrastructure (e.g. cannot receive/reply to emails from certain providers) |
| | May not be possible to provide some aspects of standard assessment or treatment |
carers were reported to find telehealth practical (e.g. less travel). Yet, others could not “speak for long enough due to having children to look after, or they are not answering the phone despite prior warning”.

Telehealth and working from home was not always ideal; for example, due to potential confidentiality breaches. One participant felt that “being thoughtful about the space in which you do a video call is especially important, [if asked about] personal items they [autistic individuals] can see in the video. This might lead to more sharing of personal circumstances than the professional would like or feel comfortable with”.

Participants providing interventions were concerned that “input via telehealth results in less intervention”. It was “challenging to deliver a communication intervention” remotely. There was some “loss of chances to implement behavioural activation strategies and exposure”, and test out skills, in CBT. Generally, participants wanted to know “more about the evidence base”.

Telehealth was a convenient method for meeting colleagues, liaising with external (multi agency) providers and delivering training. However, participants noted “a lack of clear guidance at the beginning of the pandemic [about telehealth]”, and that this only worked well with the right infrastructure (e.g. IT systems, lone working policies, training, equipment, the capacity to screen share so that clients could view diagrams).

Fig. 2. Reshaping service provision.
3.1.5. Inequalities

The fifth theme concerned inequalities. Several participants highlighted their impression that autistic individuals can be “extremely vulnerable and [yet, are] not recognised by the government as such”. Moreover, “health [services] took so long to contact those in the community” at the outset of the pandemic; as if autistic individuals were invisible, despite likely high levels of (unmet) need.

Health professionals reported autism diagnostic pathways had been hampered even more than usual. “Health visitors and school nurses” could not identify potential need or instigate referrals, due to school closures and infrequent home visits. The unavoidable move to remote working had resulted in diagnostic assessments “mostly being on hold”, with participants finding that the “downside of waiting is that it extends the (already lengthy) waiting lists and prolongs answers for the individuals/families”. This meant individuals were stuck in limbo (between services, without intervention). With “growing evidence of families in big difficulties”, delays in assessment meant respite was inaccessible.

Possible inequalities in acute medical care provision were highlighted. “Lack of adjustments in hospital settings” was concerning. Moreover, there were concerns about the reliability and validity of the Clinical Frailty Scale (CFS; a scale that assesses frailty following critical care interventions; Rockwood et al., 2005) for individuals with developmental conditions.

Reliance on teletherapy also revealed inequality. Not all clients had access to the technology required, the applications needed (e.g. Microsoft Teams), IT skills or internet connection, to use this effectively. One participant remarked that “it’s [the pandemic] about loss of future for people who already have faced all manner of adversities – people can feel even more marginalised and generally left out”.

3.1.6. Looking to the future

The final theme, looking to the future, had five sub-themes.

3.1.6.1. A change of ethos. One participant remarked “this [C-19] may be a really good opportunity to make the world a more autism friendly place”. Participants considered need/support should be evaluated on an “individual basis”, rather than being prescribed homogenously. Participants emphasised “understanding how they [autistic individuals] want this to happen”.

3.1.6.2. Policy reform. “Pre-planning for the exit strategy and what this looks like for this population [autistic individuals]”, was key, as was sufficient notice about policy changes by “government and agencies who cascade and actuate the recommendations”. Caveats to social distancing guidelines were proposed, such as “a pass at supermarkets … [autistic individuals going] straight to the top of the queue rather than [waiting].”

3.1.6.3. Research implications. Research implications were highlighted. Further investigation into “what helps build resilience or what is protective under exceptional circumstances, or even day to day life and how best to support families of children with autism” seemed pivotal. Establishing predictors for “positive outcomes” was another suggestion. Scaled up studies, focusing on “the needs of individuals … to help assess and treat mental health difficulties that may have emerged or worsened as a result of C-19” were deemed priorities for governmental investment.

3.1.6.4. Reshaping service provision. Participants identified numerous adaptations to service provision and education, to enhance support for autistic individuals, now and post-lockdown. These included outlining fundamental principles for working with this group and ways of conveying information and facilitating transitions in/out of lockdown, alongside specific ideas about easing reintegration to school and tailoring of clinical services (summarised in Fig. 2).

The need for “multi-agency working” and links between “health and education” was highlighted, to “improve provision, consistency and general support”. “Working together and listening to each other without the constraints of red tape” was viewed as essential. “Flexibility in existing care packages … dedicated mental health services” were vital for staving off long-term pandemic consequences (e.g. anxiety, low mood). One participant’s team were “looking at a lot of our processes as an inpatient setting to rethink our pathways, incorporating a clearer trauma informed care pathway”.

Most participants thought clinical services should offer blended approaches; combining in person work, teletherapy and telephone appointments. They planned to “work more flexibly across different settings”, offering a “mix of telehealth and in-person appointments to balance the differing demands”. “Provision of accessible … good quality, clear information, such as about what people need to do to keep themselves safe … community resources and support services … where patients and professionals and family carers can seek help” were vital.

3.1.6.5. Living in the ‘new normal’. Participants described how autistic individuals and their families might be best supported now and post-lockdown, in ‘the new normal’ (also outlined in Fig. 2).

3.1.6.5.1. Support for autistic individuals. One participant remarked “we have been in lockdown for many weeks now and for some people this routine is starting to become normal”. So, changing it again, and suddenly, may also cause as much stress and anxiety as the start of the lockdown”. Thus, support should be tailored. “For some people, this could mean gradual exposure, [whereas] others may tolerate rapid changes - as long as they’re informed beforehand”; highlighting heterogeneity of autism. Participants mentioned enabling autistic individuals and their families to “tell the professionals what would work best for them and help them understand it [the situation], by talking to them about it, explaining what you have to do (e.g. in a shop and why we have to follow the guidelines)”. “A phased return” and “gradual introduction to the community [and school]” were considered pragmatic. However, it was acknowledged that we may not return to pre-pandemic activities, so “our task will be more to help people adapt to the current
circumstances, whatever they may be and be explicit about what the changes are”. Thus, professionals should “assist them [autistic individuals] to establish ‘a new normal’ routine and ensure all staff members are delivering the same consistent message about changes”.

Numerous participants indicated “there shouldn’t be too many demands placed on people as this may increase distress and anxiety - as it would for any other person. People should be able to reflect and express feelings on lockdown and talk about what they didn’t like and what they liked”. More widely, some autistic individuals were anticipated to “require support to develop strategies to reduce anxiety linked to social distancing … help overcoming fears linked to grief and death, and longer-term access to therapies to provide support around longer term effects on emotional well-being”.

3.1.6.5.2. Support for families. Establishing families’ views was considered a fundamental first step, as “every family has different levels of support/need and will be impacted differently”. It was noted “parents of children may need additional support to begin to prepare children and young people returning to life”. Adequate levels of respite were deemed crucial for families coping alone with high levels of “challenging behaviours”. It was also suggested that families should be offered opportunities to “sign up to the hospital electronic records patient portal to facilitate easier access to the video calling system … and access to their child’s letters and reports”.

3.1.6.5.3. Support for professionals. For themselves - and perhaps distinctly from infrastructural changes - participants perceived additional support, training, supervision and flexibility, would aid them to deliver effective input within evolving models of support. The continued uncertainty of the pandemic was highlighted, implying that ongoing, cohesive team discussions were important.

4. Discussion

In a cross-sectional survey, we gathered professionals’ views about vulnerability factors for coping with the pandemic, the impact of C-19, lockdown and social distancing, service provision during the pandemic and strategies for supporting autistic individuals, during and post-pandemic.

Participants outlined psycho-social factors they considered render C-19 lockdown especially difficult for some autistic individuals. These included core autism characteristics (e.g. social communication impairments, difficulties tolerating uncertainty and change), particular neuropsychological traits (e.g. rigid thinking, generalisation of information), executive functioning impairments, emotion dysregulation and comorbid mental health conditions. Additionally, data indicate these factors could be compounded (in participants’ views) by lack of routine/engagement in activity, inadequate/conflicting information (e.g. about social distancing) and disruption to, or withdrawal of, services. Previous studies have reported autistic individuals struggle with lockdown (Bal et al., 2021; Colizzi et al., 2020; Oomen et al., 2021). Findings here illuminate more specific mechanisms for vulnerability identified by professionals. Further qualitative and quantitative research is needed, therefore, to better understand common and unique risk and protective factors for coping with C-19 and its impact.

Study findings highlight the impetus for health/social care professionals to assess how and why autistic individuals are experiencing difficulties currently, to inform development of personalised, formulation-based psycho-social interventions (Johnstone & Dallos, 2013). These could, for example, include cognitive behavioural interventions (e.g. to enhance tolerance of uncertainty, capacity for flexibility, emotion regulation), social skills interventions (e.g. to support individuals to feel more able to ask questions, engage in C-19 compatible activities, habituate to social contexts as lockdown eases) and systemic interventions (e.g. to identify personal/familial narratives about social distancing, address family accommodation). We will likely transition in and out of different degrees of distancing and lockdown for some time, so autistic individuals should be offered interventions now to help manage subsequent pandemic waves, and for the future. In person interventions targeting these areas (e.g. for reviews, see Conner et al., 2019; Gates, Kang, & Lerner, 2017; Rodgers et al., 2017; Spain et al., 2017) could be adapted for remote delivery, building on teletherapy for other clinical populations. Pilot intervention work should target putative risk factors for poorer coping, and strengthen resilience.

Disruptions to health/social care services were commonly reported; attributable to the temporary closure of services, redeployment, and social distancing measures. Similar disruption, or complete loss of services, has been outlined by more recent studies that have recruited caregivers (Al Samadi et al., 2020; Colizzi et al., 2020; Manning et al., 2020; Mutluer et al., 2020; Neece et al., 2020; White et al., 2020), and autistic adults (Bal et al., 2021; Oomen et al., 2021; Manning et al., 2020). Importantly, participants in these studies were based in Europe, the USA and the Middle East, suggesting that the pandemic has had far-reaching ramifications for the care and support for both autistic young people and adults. Moreover, findings from the present study support prior research that has highlighted that different types of service along the care pathway, including those that offer diagnostic assessments (Wagner et al., 2020), day centres (Al Samadi et al., 2020) and psychological therapies (Kalvin et al., 2020; Pollard et al., 2020), have been similarly affected.

It is feasible that service disruption has in/directly increased autistic individuals’ and their families’ level of stress and exacerbated carer burden. Anecdotally, we have found some health departments have regularly updated clients about what is happening (e.g. when what is closed, reasons for this, mitigating plans, emergency contact details), with several demonstrating innovation (e.g. producing easy read leaflets, self-help intervention manuals). Disruption to services may be unavoidable. Yet encouraging service-user input about how, when and what information is disseminated, and in decision-making about reactive and proactive changes to provision, seems fundamental.

Participants consistently mentioned temporary closure of diagnostic services. Even before the pandemic, it could prove difficult for young people and adults to access an assessment (Harper et al., 2019; Lewis, 2017; Martinez et al., 2018). Barriers to autism assessment and/or diagnosis include clinician-related factors (e.g. poor autism knowledge, disagreement between health professionals), service-related factors (e.g. inconsistent care pathways, few diagnostic services, lengthy waiting times), discriminatory practice (e.g. conceptualisations of autism as a ‘male disorder’, individuals from ethnic minorities less frequently diagnosed with autism) and
clinical factors (e.g. diagnostic overshadowing, complex comorbid presentations) (Walsh, Lydon, O’Dowd, & O’Connor, 2020). Yet, the pandemic context has augmented these barriers, perhaps most notably in diagnosis, due to the inherent problems in assessing constructs such as integrated gaze and facial expression (i.e., key diagnostic indicators), during mandated distancing and use of PPE.

Participants described trying to balance in person evidence-based diagnostic methods with a more clinically pragmatic remote assessment approach. A review by Alfuraydan, Croxall, Hurt, Kerr, and Brophy (2020) synthesised data from ten studies evaluating feasibility, acceptability and/or reliability of telehealth autism assessments. Studies used one of two methodologies: (1) the ‘real time method’, involving a teleconferencing-type format; and (2) the ‘store-and-forward method’, involving parents/carers sharing video footage of prescribed situations. Overall, remote diagnosis appeared tentatively promising, but replication of methods in other, larger (clinical) samples is warranted. Findings by Wagner et al. (2020; see below) are also encouraging. Research is needed to clarify the perspectives of autistic individuals, their families and professionals about remote assessment, and how best this can be adapted for individuals with and without informants (i.e., parents), and with varied clinical presentations (e.g. ID, severe depression).

More generally, strengthening interdisciplinary collaborations, with multi-agencies, was deemed critical. This may be more achievable if services/professionals have some shared aims (e.g. offering person-centred individualised care), compatible IT systems, methods for sharing documentation (e.g. communication passports, clinical reports) and open channels of communication. Implementation studies examining barriers and facilitators to multi-agency case management and service delivery, with autistic individuals in mind, would likely improve sustainability.

Most participants had used telehealth recently, either for partial assessments or ongoing therapeutic work. Study findings suggest there are ‘pros and cons’ for telehealth, for each stakeholder group. Some autistic individuals, for example, were reported to find this a more tolerable method of engagement, especially given flexibility in appointment frequency and duration; yet, others were considered to find this more confusing, or could find it difficult to engage via the screen. For parents/carers, this was deemed to be efficient, yet only with sufficient time and privacy. Professionals deemed this useful in some regards, yet organisation infrastructures were slow to catch up.

Participants’ views on telehealth mirror those described by a very recent study by Wagner et al. (2020), that examined outcomes and clinician acceptability of telehealth diagnostic assessment for young children with suspected autism. Responses to a survey indicated that clinicians (N = 9) felt ‘comfortable’ with the process of tele-assessments, including conducting the assessment, reaching a diagnostic conclusion and feeding this back to patients and their families). Yet, they also reported some obstacles, relating to IT (e.g. ‘technology-related challenges’), the environment (e.g. several people in the vicinity while the assessment was taking place), practical issues (e.g. access to documentation) and clinical considerations (e.g. patients being distractible). More generally, telehealth for autistic individuals has not previously been mainstay in the UK, although there is precedent elsewhere. A review of eight studies examining acceptability or effectiveness of telehealth assessment and/or interventions for autistic individuals found telehealth was associated with good outcomes (Boisvert, Lang, Andrianopoulos, & Boscardin, 2010). However, the combined sample, across studies, was small (N = 46), and there were some methodological limitations with study designs (e.g. single cases).

Clinically, we have found offering additional appointments to clarify autistic individuals’ preferences for using telehealth (e.g. whether to have the lights off/on, sound volume, height of camera, proximity to speaker) seems to enhance engagement. Clarity in the provision of instructions and guidance, along with repetition and consistency have also recently been identified as important aspects of remote healthcare delivery during the pandemic (e.g. Pollard et al., 2020; Sivaraman et al., 2020). Development of good practice guidelines about the use of telehealth with autistic individuals – informed by qualitative and quantitative research – could prove very useful (see Kalvin et al. (2020) for a summary of ways CBT can be adapted, and Pollard et al. (2020) for a summary of adaptations to ABA). It may also be that a hybrid model – combining telehealth with some in person work – could have merit (e.g. Ali Samadi et al., 2020).

Echoing concerns raised about potential inequalities autistic individuals may face at this time (Ameis et al., 2020; Cassidy et al., 2020; Pellicano & Stears, 2020), participants here identified several relating to daily life, capacity for (social) contact, access to diagnostic assessments, and general and mental health and well-being. Additional inequalities are reported in the EXPLORA study (Oomen et al., 2021); autistic individuals described difficulties with completing everyday tasks (e.g. shopping), partly due to lack of accessible information and accommodation of autism traits.

Contributory mechanisms for inequalities are conceivably multi-factorial, and perhaps best viewed from a systemic standpoint. A meta-synthesis of studies from the United States focusing on ‘racial, ethnic and socio-economic’ disparities in autism highlighted that familial (e.g. limited resources, managing family life), cultural (e.g. beliefs, stigma, isolation) and structural (e.g. lack of infrastructure, professionals’ knowledge/views about autism) barriers, are influential factors (Singh & Bunyak, 2019). Researching the range of inequalities that autistic individuals might experience and seeking systemic explanations for this, is a necessary step to addressing these.

Participants generously provided their thoughts about how autistic individuals can be supported to reintegrate back into their lives and communities as the lockdown restrictions ease (or become more stringent once more) and following the pandemic. Overall, it seems clear that a multifaceted approach will be needed. Legislators have an opportunity to consider what and how health and social care provision can be delivered. There is also an impetus to generate empirical evidence about impact and options for support, as currently there is a limited evidence base for remote working. Importantly, a phased return to activities, with support for autistic individuals and their families, is more likely to glean success.

4.1. Limitations

There are several study limitations. We recruited professionals solely from England, so findings may not generalise to other
countries. Participants’ views may also not be representative of those of multidisciplinary professionals working with autistic individuals, but who did not participate (e.g., social workers, family therapists, educators). We acknowledge that the sample size was very modest. Yet, the study was open when life in the UK was hugely disrupted; we considered a short recruitment period pragmatic under these circumstances, but sufficient to allow us to garner professionals’ perspectives in a preliminary study. There is a possibility of sampling or selection bias; for example, professionals who have had negative experiences of telehealth may have been deterred from participating, and professionals who have worked in services that were either quick or slow to adapt service delivery due to C-19 may have been more motivated to offer their perspectives.

4.2. Conclusions

This preliminary study captured the views of professionals working with autistic individuals, during C-19 and lockdown in England. Similar to findings from recent studies about autism and C-19 that have sought the perspectives of other stakeholders (e.g., caregivers), participants here reported that abrupt changes to health/social care provision and education, potentially place autistic individuals, individuals awaiting diagnostic assessment, and their families, at risk of developing or exacerbating short- and longer-term unmet needs and mental health conditions (e.g., stress, anxiety, depression). As we move through phases of the C-19 pandemic - trying to manage living in the ‘new normal’ while mitigating further waves - professionals will need to work collaboratively with each other (across sectors and services), and with autistic individuals and their families, to understand the impact of these extraordinary circumstances and develop ways that everyone can be supported more effectively.

Ethical approvals

The study attained ethical approvals (REF MRA-19/20-18339).

CRediT authorship contribution statement

Debbie Spain: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft, Project administration. David Mason: Conceptualization, Methodology, Formal analysis, Writing - original draft. Simone Capp: Conceptualization, Methodology, Formal analysis, Writing - review & editing. Laura Stopplebein: Conceptualization, Methodology, Writing - review & editing. Laura Stopplebein: Conceptualization, Methodology, Writing - review & editing. Francesca Happé: Conceptualization, Methodology, Writing - review & editing, Supervision.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi: https://doi.org/10.1016/j.rasd.2021.101747.

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