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‘I’m able to function better when I know there’s a beginning and an end time’: Autistic adolescents’ experiences of lockdowns during the COVID-19 pandemic

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Abstract

Background and Aims: Survey research indicates that autistic children and young people experienced high levels of anxiety and isolation during lockdowns in response to the coronavirus disease 2019 (COVID-19) pandemic. Meanwhile, qualitative studies suggest that there may have been some benefits in the switch to home learning for this population. However, the majority of evidence to date comes from parent reports; the current study aimed to triangulate the perspectives of autistic youth and their parents in order to more fully understand the impact of periods of lockdown on education, relationships, and wellbeing.

Methods: Thirteen semistructured interviews were conducted (six with adolescents, seven with parents) to explore the experiences of a group of autistic youth aged 13–14 years (Year 9 of mainstream education in England) during a period of intermittent lockdown. Data were analysed using reflexive thematic analysis.

Results: Two broad themes capturing commonality and diversity in the adolescents’ experiences of lockdown were developed. (1) “Different stress, not less stress” encapsulates the finding that, despite the enforced removal from the school environment providing short-term relief, new stressors contributed to consistently high levels of anxiety for the young people throughout lockdown periods. Stressors included managing home-school within the family unit, navigating time without boundaries, and anxiety about the virus. (2) “A shrunken world” reflects the heightened impact of losing access to meaningful social relationships, extracurricular pursuits, and health-promoting activities for autistic youth.

Discussion: The early stages of the global response to the COVID-19 pandemic caused serious disruption to education for many children and young people globally; our findings provide further evidence that the impact was particularly salient for autistic youth in terms of social isolation, lost learning, and heightened anxiety.

Implications: These findings underscore the necessity of long-term support for the education, social needs, and mental health of autistic young people in the aftermath of lockdowns in response to COVID-19.

Keywords

Autism, COVID-19 lockdown, young people, anxiety, qualitative methods

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In 2020 and 2021, over a billion school-aged children globally were impacted by lockdown restrictions in response to the coronavirus disease 2019 (COVID-19) pandemic, including school closures and a rapid pivot to online learning at home (Fore, 2020; Patrinos et al., 2022). In England, schools were closed for all but the most vulnerable pupils and children of keyworkers from March to June 2020 for some year groups and did not re-open until September for others. A second period of school closures ensued during a subsequent wave of infections between January and March 2021. The long-term impact of school closures and restrictions to social contact on children and young people's development, education, and mental health is as yet unknown, although there is early evidence of learning loss in many countries (Patrinos et al., 2022). For autistic youth, the experience of lockdown may have presented particular challenges and opportunities aligned with individuals' social, sensory, and executive characteristics. For example, learning at home likely reduced the sensory stress commonly experienced by autistic pupils in school environments (Heyworth et al., 2021). Conversely, social isolation during lockdown may have been particularly marked in this population (Pellicano et al., 2021). The current study explores the experiences of a group of autistic adolescents during the height of the COVID-19 pandemic in the UK in relation to school learning, social relationships, and wellbeing.

Studies across countries have used parent-report surveys to assess the impact of lockdown on autistic children's wellbeing (Banerjee et al., 2021; Berard et al., 2021; Jacques et al., 2021; Nonweiler et al., 2020). This research suggests an overall deterioration in sleep patterns, mental health, and behaviour. Moreover, many parents and caregivers report an increase in their own stress and anxiety, placing strain on relationships while families were confined to the home (e.g., Asbury et al., 2020; Corbett et al., 2021; Kawaoka et al., 2022). Longitudinal data indicate that autistic youth experienced high anxiety in comparison with their neurotypical peers through the early months of the pandemic (Corbett et al., 2021). Further, in a four-wave longitudinal study, parents reported high anxiety in their autistic children compared with children with other special educational needs and disabilities (SENDs) at the start of the pandemic (Toseeb & Asbury, 2021). As the pandemic progressed, anxiety levels decreased for children with other SENDs but not for autistic children. However, removal from the demands of the school environment during lockdown brought wellbeing benefits for a minority of autistic children (Asbury & Toseeb, 2022). Taken together, research to date suggests that the mental health toll of the pandemic may have disproportionately affected autistic youth at the group level, with important individual differences.

For autistic young people in mainstream education, the forced removal from the sensory and social demands of

the school environment might have facilitated learning in some cases (Heyworth et al., 2021; Simpson & Adams, 2022). Nonetheless, children with a range of neurodevelopmental differences experienced remote learning more negatively than neurotypical children in a parent-report survey study (Baten et al., 2022). The boundaries between home and school can be particularly important for autistic children, with home often experienced as a haven from societal demands. Thus, the pivot to home learning may have been posed wellbeing for this population (Canning & Robinson, 2021).

Few studies to date have directly collected input from autistic youth, with the majority of studies replying on parental reports. Research including first-person lived experiences is important for advancing understanding, practice and self-determination (Bailey et al., 2015; Tesfaye et al., 2019). Heyworth et al. (2021) conducted interviews relating to educational experiences with 16 autistic young people, alongside a larger sample of parents, in the early stages of the pandemic in Australia. Their findings suggest that, while the initial transition to remote learning was difficult, many autistic students thrived at home during these early months of lockdown. Young people reflected that removal from the school environment had allowed them more time to decompress, space to reflect on their ways of learning, and flexibility to study at a pace that suited them. However, social isolation during the early months of lockdown was experienced as intensely detrimental to wellbeing in this study; both autistic youth and adults described deeply missing in-person interactions with friends, as well as more peripheral social contact (Pellicano et al., 2021). Pluquailec and O'Connor (2022) conducted family interviews with autistic young people and their parents in the UK, with young people directly participating in three of nine interviews conducted. Findings indicated a rich variety of experiences. For some young people, greater physical autonomy at home led to improved focus during home learning; some enjoyed the opportunity for self-directed learning. Young people did not universally experience the frequent change between home and school settings as negative; indeed, greater flexibility in the mode of learning could be experienced as a benefit.

More research that includes the first-person perspectives of autistic young people is needed in order to gain a fuller understanding of the impact of COVID-19 on learning, development and wellbeing (Pellicano & den Houting, 2021). The current study reports a qualitative analysis of interviews conducted with autistic adolescents during a period of intermittent lockdown in England. Parents' perspectives were also sought to triangulate with young people's accounts (Bölte, 2014). Our overarching research question in this study was: How did experiences of intermittent lockdown in response to the COVID-19 pandemic impact autistic adolescents' learning, social relationships, and wellbeing? Increasing knowledge of this topic can

inform educational and healthcare practice in supporting autistic youth to flourish beyond the specific context of the pandemic.

Methods

Context and study design

The dataset for this study is taken from the final timepoint of a 4-year qualitative longitudinal study of autistic pupils' experiences as they progressed into and through mainstream secondary education (Mesa & Hamilton, 2022a). Ethical approval was obtained from York St John University Ethics Committee. The aim of the wider, longitudinal study was to gain a holistic understanding of the barriers to, and facilitators of, positive educational outcomes for autistic pupils in secondary education over a period of years, triangulating data from multiple stakeholders (Mesa & Hamilton, 2022b).

Families were recruited to the longitudinal study via the specialist teaching team at the local education authority in 2017. We targeted pupils who were about to make, or had recently made, the transition from primary to secondary school and who had received a formal diagnosis of autism by a clinical professional. We interviewed autistic pupils, their parents and teachers annually from Year 6 (final year of primary education; aged 10–11 years) to Year 9 (third year of secondary education; aged 13–14 years) on various aspects of the pupils' educational experience, including classroom learning, peer relationships and bullying, the physical school environment, and extracurricular interests and activities (Mesa & Hamilton, 2022a).

The final data collection point of the longitudinal study for seven families fell during the COVID-19 pandemic (October 2020 to February 2021). During these interviews, we again asked about aspects of the young people's school experience, and also asked how the containment measures in response to the pandemic had impacted these experiences. The dataset for the current study, therefore, comprises 13 interviews that were conducted against the backdrop of the COVID-19 pandemic. This included six youth interviews (one young person did not wish to take part in an interview at this timepoint) and seven parental interviews (six with mothers; one with both mother and father).

Participants

All participating families resided in a city in the north of England and identified as white British. We recorded parental occupation status as an indicator of family socio-economic status (SES); this ranged from long-term unemployed to higher professional occupations indicating a mixed-SES sample (ONS, 2020). Young people were in Year 9 (age 13–14 years) in mainstream comprehensive secondary

schools at the time of the interview. The group of autistic young people included six boys and one nonbinary youth.

Parents completed the Social Communication Questionnaire (SCQ lifetime version; Rutter et al., 2003) in relation to their child at the outset of the longitudinal study. The SCQ is a screening measure for autism, comprising 40 items relating to the developmental history of social communication support need, with a suggested cut-off score of 15 indicating possible autism. The mean score in the current sample was 21.29 (range 15–27) indicating a wide range of social communication support need. Several young people in the sample had co-occurring diagnoses of neurodevelopmental, mental health, or chronic physical health conditions. Some of the young people had been home-schooled through each lockdown period; others received a priority school place after the first lockdown. Table 1 provides demographic, diagnostic, and contextual information for each young person.

Data collection

We conducted semi-structured interviews with young people and parents separately via Microsoft Teams. However, young people could choose to be interviewed with parents present; two adolescents opted for this. While parental presence may have influenced the young people's responses, we prioritised giving adolescents autonomy to choose how they were most comfortable participating in the interviews, given the extraordinary context of the pandemic. The interview schedule comprised questions relating to young people's school experiences (e.g., academic learning, peer relations, access to specialist support) in common with previous years of data collection. We also asked specifically about periods of school closure due to national lockdowns, using follow-up questions to probe participants' responses further as appropriate (see Appendix for interview topics and sample questions). Interviews last for an average of 21:31 min (young people); 46.73 min (parents) and were recorded and subsequently transcribed verbatim. Identifying information was removed during transcription to preserve families' anonymity.

Throughout data collection, we were guided by the recommendations for conducting research with autistic people set out by Cridland et al. (2015). Young people were interviewed by the same researcher as at previous timepoints, and were familiar with the question schedule. Interviews at earlier phases of the longitudinal study had been conducted in person; we therefore discussed the switch to an online format with parents, who prepared young people for the change. Young people were familiar with the MS Teams environment from remote schooling.

Data analysis

We conducted an inductive, reflexive thematic analysis of the interview data (Braun & Clarke, 2006, 2021), aiming to give an account of the young people's experiences

Table 1. Sample characteristics.

Pseudonym	Gender	SCQ score ^a	Co-occurring conditions	Parent interviewed	Highest parent occupation ^b	Lockdown education
Robin	Male	24	Anxiety and depression	Mother	L14 Long-term unemployed	Priority school place 2021
Jordan	Non-binary	15	Chronic physical health condition	Mother	L8 Employer in small organisation	Home learning throughout
Henry	Male	15	n/a	Mother and father	L3 Higher professional occupations	Home learning throughout
Ewan	Male	24	ADHD	Mother	L10 Lower supervisory occupation	Priority school place 2021
Oliver	Male	27	ADHD	Mother	L4 Lower professional/higher technical occupations	Priority school place 2021
Peter	Male	22	n/a	Mother	L4 Lower professional/higher technical occupations	Home learning throughout
Charlie ^c	Male	22	PDA	Mother	L3 Higher professional occupations	Home learning throughout

SCQ = Social Communication Questionnaire; PDA = Pathological demand avoidance.

^aScore on the Social Communication Questionnaire (lifetime version; Rutter et al., 2003). Scores of 15 or above indicate possible autism.

^bCategorised according to the Standard Occupational Classification (Office for National Statistics, 2020).

^cNo child interview data available.

during the lockdown and the ways in which they and their parents make sense of these experiences. We adopted a critical realist perspective, foregrounding meaning-making from experience, and acknowledging the role of sociocultural and temporal context in this process (Bhaskar, 2008). Critical realism links realist ontology with subjectivist epistemology, allowing for mixed- and multi-method approaches to knowledge generation and centring the reflexivity of the researcher (Botha, 2021; Kourti, 2021). The interviews took place during an unprecedented global health emergency, during which familiar social contexts (schools, workplaces, neighbourhoods) were severely disrupted, and so the critical realist lens was especially relevant. More broadly, the study is grounded within the neurodiversity paradigm, with a focus on the interaction between individual and environment in understanding experiences and functioning for neurodivergent young people (Chapman, 2021; Dwyer, 2022).

Reflexive thematic analysis is an interpretative methodological approach, in which the importance of the researcher's subjectivity in developing the analysis is explicitly acknowledged (Braun & Clarke, 2021; 2022). In adopting this analytic approach, principles of reliability, validity, and generalisability were not relevant. Instead, we aimed to ensure the authenticity and trustworthiness of our analysis as follows. We followed a recursive analytic procedure in developing the themes. All authors listened to the interview recordings and read accompanying transcripts several times, noting and discussing observations on each interview and the dataset as a whole. The first author then coded all transcripts, generating a combination of semantic (descriptive) and latent (interpretative) codes for any data of

relevance to the aims of the study, while noting possible meanings participants were ascribing to their experiences. The reduced dataset (i.e., parts of the interviews coded in the first iteration as relevant) was next coded afresh by the second author and the set of codes developed and revised (e.g., similar codes collapsed) through discussion. At this stage, we collated data excerpts relevant to each code and developed a working thematic structure, encapsulating meaningfully related codes. We discarded sub-themes defined by limited data or integrated them with other themes. During this process of theme refinement, we revisited the full interview dataset to ensure that the thematic structure was representative of the breadth and diversity of experience related by the participants, with a focus on potential disconfirming cases. As we finalised the thematic structure, we developed definitions for each theme and sub-theme, further analysing the data attached to each in terms of participants' meaning-making. We then identified key data excerpts to include as illustrations of our thematic structure. Throughout the analytic process, we explicitly reflected on how our own experiences and prior assumptions may have shaped the data analysis presented and summarise this in a reflexive statement in the Discussion section.

Results

Demographic characteristics of each adolescent, and information on their patterns of schooling through the pandemic, are set out in Table 1. In the analysis that follows, the pseudonyms listed in Table 1 are used to identify excerpts from interviews with young people; parent data

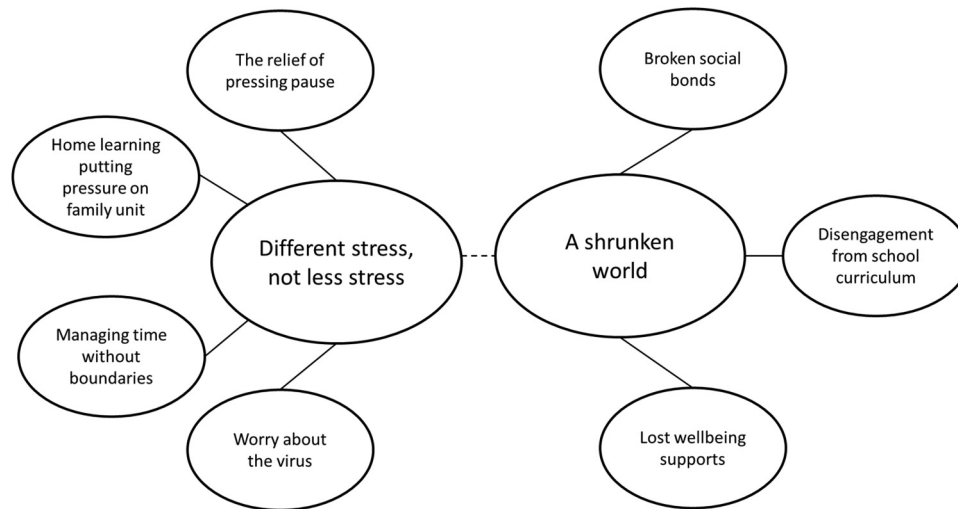


Figure 1. Thematic map.

is identified by reference to the young person's pseudonym (e.g., "Robin's parent").

Our reflexive thematic analysis resulted in two related themes, each with several subthemes (Figure 1). *Different stress not less stress* (Theme 1) denotes the finding that, while the periods of lockdown brought relief from the stressors of day-to-day life in the school environment (1a: *The relief of pressing pause*), new stressors linked to the pandemic meant that young people nonetheless experienced heightened levels of anxiety through this period of intermittent lockdown. New sources of stress included *home learning putting pressure on the family unit* (1b); *managing time without boundaries* (1c); and *worry about the virus* (1d). *A shrunken world* (Theme 2) relates to the diminished social contact and activity experienced by people the world over during the height of the pandemic, but highlights the specific salience of these changes for autistic youth. *Broken social bonds* (2a), *disengagement from the school curriculum* (2b), and *lost wellbeing supports* (2c) all impacted the young people through the pandemic period.

Theme 1: Different stress, not less stress

During lockdown periods, young people were removed from stressors in the physical and social school environment, which was often experienced as a relief in the short term given that busy mainstream school environments can be aversive for neurodivergent pupils (Mesa & Hamilton, 2022; Goodall, 2018). However, increased pressure on the family unit, removal of boundaries between home and school contexts, loss of routine, navigating changing regulations, and fear of spreading the virus simultaneously increased anxiety. We note that, while young people talked about things that they were finding difficult, they rarely referred directly to their own emotional states. In contrast, parents explicitly described

changes in young people's mood, emotion regulation and behaviour at home as the pandemic progressed.

The relief of pressing pause

The strict lockdown in the early stages of the pandemic was often conceived as a welcome break from stressors in the school environment. For example, the chronic bullying that Robin had experienced was interrupted; anxiety caused by managing toileting issues at school was eased for several young people; and removal from busy school environments, including corridors, dining halls, and transport, reduced sensory stress. The opportunity to 'drop the mask' at home contributed to an improvement in mental health for some young people:

I think I feel better in the lockdown. [Jordan]

They do suffer from depression... They'll have days where they're quite down and can't really operate or do anything, but those are a lot less I think because of lockdown. I think they get very overwhelmed socially. [Jordan's parent]

Fred's parent discussed his history of school refusal in light of his PDA diagnosis; for Fred, academic demands and conflict with peers at school frequently became overwhelming. In a sense, the lockdown seemed to "level the playing field" for Fred.

I really think there was so many positives to lockdown for him. The sort of intensity of school gone. He still had his friends online. I think his mental health was definitely there. [Fred's parent]

However, while school closures brought a reduction in social and sensory demands, this was balanced against young people's need for intellectual and social stimulation. Most welcomed the return to a changed school environment after the first lockdown. When schools fully reopened in September 2020, interaction with peers was restricted to year group "bubbles," and movement through school buildings was limited to reduce transmission of the virus. These new arrangements brought benefits; for example, Peter talked about his return to school during an interview conducted when he had reverted to home learning in early 2021:

I was in a Year 9 bubble and that was good. We didn't move around, we stayed inside the same classroom. Both me and my friend found lunchtime a lot better because it's not all the different years. I think we both get a bit nervous if there's a whole lot of people. And you feel like you're more used to the people, because you're with them every day. In Year 8, I'd been at school for a fairly long time but every time I went out to change classrooms, I didn't recognise most of the people. I must have seen them loads of times before, but I've not really registered it. But now I feel like I know most people's names. It's a big benefit, I think, to know. [Peter]

In summary, the forced removal from school in March 2020, followed by reintroduction to a changed, less busy school environment later that year, reduced social and sensory stress for young people over a period of months. This respite from "school-as-normal" was commonly experienced as an opportunity for decompression, comparable with the experiences of autistic adolescents reported by Heyworth et al. (2021).

Home learning puts pressure on the family unit

While school closures brought a short-term reduction in stress, the young people often faced new challenges at home. For some, adjusting to the breakdown of the boundary between home and school was difficult. Whereas home had previously been a sanctuary from the stresses of the school environment, it now took on a dual role as classroom too.

The assessments and revising at home is something I struggle with. ... It feels a bit odd doing the whole of my schoolwork at home and that could be where the struggle comes from. [Peter]

[Online learning is] essentially just homework. [Jordan]

I didn't like [homeschool]. Normally at school the teachers can help you and you can chat to your mates if you're bored. [Oliver]

The adolescents and parents alike struggled to adjust to parents taking the role of "teacher," which could lead to tensions in family relationships. Fred's parent reported that "he'll just go under a blanket and close down, cos he doesn't know what's next and we can't seem to engage him" [Fred's parent], while Ewan described his parents as "naggy" when trying to keep his schoolwork on track at home. Ewan's parent elaborated:

He loved doing cookery at school. Me and Ewan don't do cookery lessons very well together. It's very difficult. I feel like he's not getting the same quality of teaching as he would. It's not the same one-to-one with the teaching assistant, which pushed him on. [Ewan's parent]

One parent described the challenges of being isolated in a small apartment with several young children during lockdown, while trying to support home learning:

As soon as I sit down with Robin, [younger sibling]'s throwing things at me [saying] "mama mama" and it's just so difficult. Sometimes we're doing his work at eight, nine o'clock at night cos it's the only time I've got spare when [sibling] is asleep. I'm not a teacher you know. I'm trying my hardest but I have a busy life and I'm a single mum. We had to isolate together so it has just been me and the kids and they expect miracles and I can't do it. [Robin's parent]

Adolescents and parents also reported increased conflict with siblings during the lockdown periods; for example, Oliver and his sibling clashed while playing video games, while Peter recognised that his academic workload was higher than that of his primary-aged siblings, which could lead to frustration. These accounts supplement findings from existing research indicating elevated stress for both autistic youth and their parents during the pandemic (e.g., Kalb et al., 2021; Toseeb & Asbury, 2021), in part driven by the breakdown of the home-school divide creating radically changing routines and placing strain on family relationships (Canning & Robinson, 2021).

Managing time without boundaries

The sudden switch away from the structured timetable of the school week during lockdown periods could be disorienting. The young people talked about the loss of temporal markers, both broadly in terms of daily and weekly routines and specifically in the context of remote learning. For Henry, speaking while working from home during a lockdown, the switching between asynchronous and synchronous lessons, interspersed with periods of school opening, was unsettling:

I was actually wanting school to come back. I was wanting something to work towards if you know what I mean. Previously our school has just sent us work by Google Classroom, which isn't the most riveting. It's also harder to actually engage than in a properly structured lesson. But I think I'm getting more out of [synchronous online lessons] currently because I'm able to function better when I know there's a beginning and an end time. [Henry]

Peter described the extra pressure of managing his time independently during asynchronous online learning:

When there's a live lesson, the teachers tell you when to stop doing a task. If there's a task on a slide you're supposed to do, you can't always tell 'This task is supposed to take six minutes. If you go over this amount of time, you'll have to move on to the next thing.' I'm not very good at going through the slides independently thinking about all the different timings. I'm not really struggling with most of the work, but I get stressed about it because I feel like I'm not finishing anything on time. At the top you can see all the people that are on [the live lesson] and at the end of the lesson they start going. And I start thinking 'Oh, I shouldn't still be on this if other people are going off' but then I feel like I haven't got very far into it. Sometimes, when I do get stressed enough to not think clearly, I can't answer the question because I'm focusing on something I shouldn't be, which is the time. [Peter]

For Henry and Peter, the absence of external cues, such as teachers guiding the lesson structure, made time management difficult during online learning. Explicit instructions about how long to spend on each activity, both in synchronous and asynchronous lessons, were crucial, and where these were absent, young people often experienced high levels of anxiety that were likely hidden from school staff. Congruent with findings of a study eliciting autistic young people's perspectives using photovoice (O'Hagan & Byrne, 2022), lockdown learning appeared to bring new executive function demands, such as working out what tasks to prioritise and planning unstructured time effectively, and schoolwork could sometimes become overwhelming.

Worry about the virus

In addition to the stress of adapting to online learning, young people grappled with the uncertainty of COVID-19 more broadly. Several followed the progress of the pandemic through news channels and government statistics. Applying the rapidly changing regulations flexibly across contexts could be difficult. The young people talked about these issues in largely factual terms, while parents

described the perceived impact on their children's behaviour and emotion regulation. For example, during the third lockdown, Ewan said that he would not go outside, except to school, because "I'd rather not be infected by COVID" [Ewan], while his parent described an increase in compulsive behaviour at home:

He's washing his hands every time he coughs, sneezes, puts his hands on his head. Even at home, if he's sat on the computer he has a soap pump next to him, so I guess he's become quite a germophobe. It's distinguishing what you can do at home and what you can and can't do at school. [Ewan's parent]

Similarly, while Peter did not explicitly describe being worried about the virus, his parent reported an increase in compulsive behaviours at home through the pandemic:

He gets stuck in circuits. He's got this idea that he can close a door wrong, so he has to open and close the door three times and turn the tap so many times. At the beginning [of the pandemic], all of these things didn't kick in until immediately before he was due to go to bed. Having to tuck in all the chairs at the dining table, straightening the baskets he keeps his stuff in. Then it's started to, as time's gone on, leech out into other things. Going to the toilet during the day, washing hands, apologising is the biggest thing at the moment. [Peter's parent]

Observing other people breaking the rules could be particularly difficult. For example, Henry was highly aware of trends in the data related to the progression of the virus:

I've been following the news about coronavirus. I've been watching the charts and you see the deaths are about two weeks delayed from infections. The infections have been going quite down but I think it'll make people flatten the rules and that means it'll go back up again. [Henry]

Henry did not talk directly about his emotional response to these trends. However, his parent described a family funeral, where mourners shook hands and hugged in contravention of the social distancing rules:

You could see the tension in him, because they shouldn't be doing it. You could almost see him physically squashing the desire to say [something], almost writhing trying to keep a lid on it. [Henry's parent]

Similarly, Ewan's parent described a shopping trip when another customer got "very, very close" to Ewan, which he found distressing as he was concerned about transmission. Elevated anxiety specifically related to COVID-19 has been reported in a survey study of autistic youth in

comparison with neurotypical peers (Corbett et al., 2021). While young people in the current study did not often explicitly talk about their emotional response to the pandemic during the interviews themselves, parents' descriptions of their behaviours at home suggest that many were experiencing high levels of anxiety about contracting or transmitting the virus, or the application of rapidly-changing rules across contexts.

Theme 2: a shrunken world

The periods of lockdown also disrupted the adolescents' access to opportunities outside the home that were meaningful to them. They and their parents described a loss of positive social interaction with friends and mentors; a reduction in the intellectual challenge in subjects of expertise; disruption to important health supports and extra-curricular activities.

Broken social bonds

Several of the young people identified friends within their peer groups, but interactions were limited to the school context. They often did not have contact details to allow them to be in touch with schoolmates during lockdown periods, and were uncertain how to negotiate friendships beyond the school gates.

I haven't got the confidence to bring up the topic of getting each other's numbers or contact details. I could look into it, but I'm not sure how. I could ask for school email, but I'm not sure how many people actually use the school emails for anything other than checking their work once in a while. [Henry]

I texted [friend] but he doesn't have [his own phone] any more. So then I communicated with him through his mum, but that means his mum has to read the text and take it to [friend], so I don't know. [Peter]

I think if somebody said, 'Shall we swap phone numbers?' he would just think it wasn't really his place to do that. [Oliver's parent]

Thus, young people were motivated to maintain contact with friends while they were physically separated by lockdown, but were often unsure how to make this happen; and it was notable that their peers had not taken the initiative in maintaining contact. On return to school following the lockdown, social groups at school had shifted, which could be difficult to negotiate. For instance, Oliver found that he was no longer part of a friendship group that he had belonged to before the lockdown. Henry had thought that he might have a chance to join established friendship

groups at school, envisaging that school post-lockdown might be like "starting anew" [Henry]. However, this proved difficult to implement when schools re-opened in late 2020. Moreover, the lockdown brought an end to a mentoring relationship with an older student, with whom he had been used to discussing his extensive knowledge of world events.

Thus, the pandemic brought a disconnection from helpful social links for the young people, which parents described as having a profound impact on behaviour at home:

He's had periods of having more self-awareness than he has at the moment. That strikes us as due to a lack of access to the outside world and other people. The situation is reduced to the immediate family and he has effectively regressed. He reduces himself down to his current situation, which is: It doesn't matter what other people are doing because I'm here doing this, and that is the whole of the world now. [Peter's parent]

On the other hand, where adolescents had been experiencing problems with peers, the reduced social interaction of lockdown was perceived as helpful. Robin and Charlie, who had experienced chronic bullying at school, were able to maintain more positive interactions with friends via online gaming and social media. Jordan found that it was easier to focus on positive peer relationships during this period:

What's good is I've kind of distanced myself from the people who made me feel overwhelmed and I have a good group of friends, you know, I can chat with and hang out with away from the other people who make me feel overwhelmed. [Jordan]

In summary, some young people were very isolated from peers during periods of lockdown, and were unsure how to maintain relationships outside the family outwith the structure of school. However, for others, the enforced reduction in social contact brought respite from problematic peer relationships at school and the opportunity for more positive interactions either online or in less crowded social spaces. In an interview study with parents, Fox et al. (2022) reported a similarly diverse range of impacts of the pandemic on autistic children's friendships.

Disengagement from school curriculum

For the young people in this study, lockdowns fell during the preparatory years for General Certificate of Secondary Education exams; parents expressed concerns about the amount of missed material and learning support and the potential impact on their attainment. Ewan struggled to

maintain attention in online lessons. Pre-pandemic he had worked with a teaching assistant who helped him keep focus and move through tasks; during the second and third lockdowns he was joining lessons remotely in the specialist autism unit at school:

Academically he's lost a lot. He lost his mojo where school was concerned. If he's sat with his headphones on at a computer desk, how can a [teaching assistant] help him if they're not on the same [device]? [Ewan's parent]

The young people also talked about disengagement from lessons during home learning, often showing insight into their individual attention differences:

I didn't like home learning ... It was just boring. [Oliver].

Sometimes I just snooze out in my own little bubble. [Ewan].

I always end up switching off in Maths and then I never understand what we're doing and then then they have to explain it again and I end up switching off again. I've got a problem with that. [Robin]

The thing with school is I struggle to do things I'm not interested in, but I have no problem doing things I am interested in. But at home, it's like a more extreme version that. [Jordan]

Jordan described how they disengaged from much of the core school curriculum during home learning, instead pursuing independent research in an area of specialist interest. This opportunity to focus on individual interests was liberating; however, the lost curriculum learning had a significantly negative impact on their grades at the return to school. Oliver's parent perceived that his academic skills had been under-estimated before the pandemic, such that he was often placed in a set below his ability level. His disengagement when learning from home may have exacerbated this trend:

I think he may be capable of more than what's being asked of him. I got an insight into it when we were doing home learning. He'll be asked to label something and he'll scribble silly comments. More often than not he's allowed to get away with it, because they can't be bothered arguing with him or possibly because they feel he's given his best level of response. [Oliver's parent]

There is limited evidence on the impact of school closures on the academic attainment of pupils with SENDs; early data indicates similar or greater learning loss compared to peers in the UK context (EEF, 2022; Webster et al., 2022). The reduction in supports impacted engagement in

lessons and perceived academic progress for some autistic pupils in the current study.

Lost wellbeing supports

Periods of lockdown brought disruption to mental health services, physical exercise, and meaningful extracurricular activities; the impact of these changes on young people was largely discussed by parents. For example, Robin had been due to commence group therapy following many months of self-harm and suicidal ideation. However, face-to-face therapies were suspended at the first lockdown, and Robin's parent reported that the replacement fortnightly telephone check-in was of limited help. Similarly, Jordan lost access to counselling at school. Often schools' capacity to support pupils' mental health, while simultaneously managing the pivot to online learning, was depleted. One parent observed, "There's just too many children in crisis. But these autistic children need more I think." [Charlie's parent]

Physical exercise was also curtailed for several of the young people during the lockdown periods. Ewan reported that he was playing video games during P.E. lessons and was reluctant to leave the house outside school hours, because "one, I'd rather not be infected by COVID and, two, because I hate exercise" [Ewan]. Henry's parents described how difficulty applying COVID-19 regulations flexibly, and anxiety about the transmission of the virus, meant that he often did not leave the house for days at a time:

He'll say things like, 'Well we're not allowed out'. He'll get very upset about it. We'll say, 'Well you're allowed out for an hour's exercise'. It did cause a whole lot of angst for him, the thought of going out. [Henry's parent]

The adolescent participants also lost opportunities to take part in school trips, family holidays, and extramural activities during the lockdowns. Parents perceived out-of-school activities to be particularly meaningful, because they allowed the young people to pursue specialist interests and talents that were not explored in depth in the school curriculum, and/or to interact with others in a less busy environment than their regular school classes. Examples included a debating club, allowing one of the young people to harness their expertise in current affairs in interaction with older students; volunteering for a community charity, drawing on an interest in health and social care; and membership of a community jazz band. Parents expressed concerns about the loss of these opportunities to pursue interests, build life skills and make friends. For example, Ewan had joined a local youth club shortly before the first lockdown:

He only went twice a month, but he was starting to get a really good rapport with the other kids there and he

enjoyed it. He got to play on the Playstation with somebody there. They'd play pool together, they'd build stuff together, draw together. It was giving him that out-of-the-house time. That's been a year now since he's been really. For somebody who finds it difficult to find friends, it was a really good thing for him to be doing. [Ewan's parent]

The loss of these extracurricular opportunities meant that several of the young people were further isolated, and parents described them as listless or anxious as a result:

Not being able to access his other activities seems to bring the anxieties into the household. He doesn't seem to have an interest at the moment; he isn't deeply engaged with anything. It's like he's waiting for something all the time. [Peter's parent]

In summary, the social and interest-based opportunities that were meaningful to the young people pre-pandemic were severely curtailed during lockdowns, as were physical and mental health supports. The autistic young people rarely discussed these changes directly; meanwhile, parents expressed concern about the long-term impact on their children's wellbeing and development.

Discussion

This study provides an in-depth analysis of seven autistic adolescents' experiences during the height of the COVID-19 pandemic, foregrounding young people's own accounts alongside those of their parents. Existing survey research indicates that autistic youth experienced disproportionately high levels of anxiety during national lockdowns, without the decrease over time described in other populations. Toseeb and Asbury (2021) suggest that one explanation for this pattern is that "the source of the anxiety changed" (p.17) over the course of the pandemic. This idea is supported in our data. At previous timepoints, the young people in our study experienced high anxiety linked to aspects of the school environment, such as the pressure of masking and chronic bullying (Mesa & Hamilton, 2022b). The rapid pivot to remote learning from home provided short-term relief from these stressors. Nonetheless, parents described an increase in obsessive, compulsive, and withdrawn behaviours at home through the lockdowns. Young people's accounts offer insight into new stressors potentially underlying these behaviours; e.g., managing the free flow of time without the familiar structures of school, increased isolation and worry about contracting and/or transmitting the virus. Autistic young people are at elevated risk of poor mental health at any time (Lai et al., 2019). It is important that practitioners supporting young autistic clients are sensitive to the specific impacts of lockdown in this group.

The transfer of schoolwork to the home environment brought new challenges and opportunities for autistic pupils (Simpson & Adams, 2022). Existing research has underscored the importance of the quality of communication and relationships between families and school staff in making this shift work effectively (Baten et al., 2022; Lipkin & Crepeau-Hobson, 2022). In our study, home learning often put considerable pressure on the family unit, particularly where there were several children in the home, where there was less structured guidance and synchronous online teaching available from schools, and/or where the autistic young person had more complex needs. For some young people, homeschool brought the opportunity to research topics of specialist interest independently and in depth; however, this could come at a cost to learning of the core curriculum and subsequent attainment. In line with findings of other studies (e.g., Canning & Robinson, 2021), some young people in our study experienced homeschool as an invasion of a necessary safe haven. Autistic pupils are already at increased risk of school exclusion and academic underperformance in relation to ability (DfE, 2019; Keen et al., 2021). The impact of lost learning during lockdowns on attainment in this group should be tracked and mitigated to avoid exacerbating existing educational inequalities.

National lockdowns and distancing regulations inevitably shrank social networks the world over at the height of the COVID-19 pandemic. For autistic young people, the impoverished opportunity for interaction may have especially far-reaching consequences. Contrary to the social motivation hypothesis, research conducted by and with autistic people indicates that reduced interest in meaningful social relationships is not characteristic of autism (Kapp et al., 2019). In an Australian study conducted during the early months of the pandemic, autistic adults and young people expressed a deep sense of social loss, missing both meaningful interactions with friends and more incidental social contact. This social disconnection contributed to a significant worsening of mental health (Pellicano et al., 2021). In the current study, it was notable that several young people were motivated to (re-)establish contact with peers during lockdowns, but often lacked the means to do so because they "wouldn't think it their place to ask for contact details". Peer interactions were therefore limited to periods when schools were open. The disruption of mentoring relationships and suspension of extracurricular groups for long periods further reduced the social contact that mattered to the young people. Some rarely left the family home for fear of transmitting the virus or contravening regulations, which further contributed to isolation and reduced health-promoting physical activity (Garcia et al., 2021). Conversely, for those who had experienced significant social difficulties at school, lockdowns offered respite from bullying and conflict, and an opportunity to focus on positive peer relationships online. These findings challenge common stigmatising assumptions about autistic sociality, and illustrate how factors other than

limited intrinsic social motivation contributed to high levels of isolation among autistic people during the COVID-19 pandemic (den Houting, 2020).

Recent theoretical accounts of neurodiversity highlight that impairment at the individual level becomes “harmful” only in interaction with the contexts in which neurodivergent people live (Chapman, 2021; Dwyer, 2022). Such accounts necessitate a shift in research focus towards the external factors that determine the function (in addition to individual-level characteristics). A growing body of research centring first-person perspectives demonstrates how typical mainstream school environments can be aversive for autistic pupils (e.g., Goodall, 2018; Williams et al., 2017) and contribute to high levels of exclusion, school refusal, and poor mental health in this population (Brede et al., 2017). The relief afforded by a period of time learning outside the school environment in the early stages of the pandemic is therefore unsurprising (Heyworth et al., 2021). However, interviews in the current study were conducted when COVID-19 containment measures had been in place for several months, and the mixed experiences of the adolescent participants at this timepoint indicate a more complex picture. The putative wellbeing benefits of time away from school were set against the loss of potentially protective external factors, such as extracurricular interest groups, positive peer interaction at school, and mental health services. High anxiety, social isolation, and disengagement from school learning were commonly reported by the participants during this time window. Long-term monitoring and support of autistic pupils in the aftermath of the pandemic is needed to ensure positive academic and mental health outcomes.

Reflexivity and limitations

Open acknowledgment of the researchers’ subjectivity and its impact on the research process is central to reflexive thematic analysis (Braun & Clarke, 2022). The interviews conducted and analysis developed in this study were shaped by our familiarity with the participating families, built over four years of a longitudinal study. Our interpretation of the young people’s experiences during periods of lockdown is therefore made in the context of our (inevitably partial) knowledge of their journeys through mainstream education during the preceding three years. Established relationships with the adolescents and their parents allowed us to gain a privileged insight into their lived experiences during an extremely challenging time period and potentially reduced the social “distance” between researchers and participants. However, they likely also directed our attention to particular aspects of the data. To address this, we coded the full dataset in iterative cycles, actively seeking unexpected or disconfirming cases to incorporate in the analysis. Our theoretical understanding of autism as neurodiversity, and adoption of a critical realist lens, meant that the analysis

foregrounded the role of social, physical, and temporal context in seeking to understand the young people’s experiences.

This study has a number of limitations. As a small-scale qualitative study, the sample cannot be representative of the autistic population, but it is notable that autistic girls and young people of minoritised ethnic backgrounds are unrepresented, which may limit the transferability of the analysis (Botha & Gillespie-Lynch, 2022). Further, the sample only included young people who were willing and able to share their experiences in an interview format; greater use of creative methods to elicit the perspectives of nonspeaking autistic young people is needed. The presence of parents in two adolescent interviews may have constrained the responses they gave, as we prioritised young people’s autonomy and comfort in the unfamiliar context of an online interview. We largely rely on parents’ perceptions of their children’s emotional states (e.g., anxiety) since the adolescents tended to talk about difficult experiences, but rarely explicitly about their emotional responses to those experiences. This could be due to alexithymic traits, developmental stage, and/or discomfort with sharing personal information in the context of a research interview. We sought to triangulate interview data from young people and parents to give a holistic account of lockdown experiences; however, we are mindful of double empathy barriers in interpreting emotional states across neurotypes on the basis of behaviours (Milton, 2012). The use of alternative methods, such as body mapping, might have allowed the young people to communicate their emotional states more directly.

Conclusion

This study illustrates diverse experiences of lockdowns in response to COVID-19 among autistic adolescents in mainstream secondary education. Respite from sensory and social challenges at school, and intermittent return to a changed, less busy school environment were often experienced positively in the short term. However, the elevated anxiety, disengagement from the school curriculum, and social isolation experienced by autistic young people as this global health crisis progressed highlight the importance of long-term provision to support mental health, educational catch-up, and social needs in this population.

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Appendix: Interview topics and sample questions

Appendix 1: List of topics covered in semistructured interviews with young people and parents, with sample questions. Concrete prompts were attached to each open-ended question as needed (e.g., Is there anything that helps you to learn in class? Prompts: teaching assistant—fidget toys/spinners—movement breaks).

Young person interview	Parent interview
<p>Topic: Classroom learning</p> <p>Is there anything that helps you to learn in class?</p> <p>Is there anything that makes it harder to learn in class? How do/did you like learning online from home during lockdown?</p> <p>Topic: Support at school</p> <p>What would you do if you were feeling worried or stressed at school?/ while you're learning at home?</p> <p>Topic: Physical/sensory school environment</p> <p>Where do you feel most comfortable at school? How comfortable does it feel doing schoolwork at home during lockdown?</p> <p>Topic: Peer relationships</p> <p>Has it been possible for you to be in contact with friends/ mentors during lockdown? [If yes: how? If no: why not?]</p> <p>Topic: Interests and extracurricular activities</p> <p>Tell me about what you like to do when you're not doing schoolwork. How have [these activities] changed during lockdown?</p> <p>Topic: Specific to COVID-19 context</p> <p>Are you looking forward to school going back to normal? Why/ why not?</p>	<p>What accommodations or adjustments does [child] receive in class (if any)?</p> <p>Which aspects of classroom learning does [child] find particularly challenging (if any)? How did [child] cope with the switch to online learning during lockdown?</p> <p>What pastoral support is available for [child] at school?/ during lockdown?</p> <p>How does [child] navigate the school environment? How has the family adjusted to [child] doing schoolwork at home during lockdown?</p> <p>What impact has lockdown had on [child's] relationships with friends/ mentors?</p> <p>How does [child] like to spend their time when they're not at school? How have [these activities] been impacted by lockdown (if at all)?</p> <p>Can you tell me about any changes in [child's] behaviour since the start of the pandemic?</p>