

The experiences of autistic young people & their parents of lockdown & the reopening of schools

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Contents

Summary	5
1. Introduction	6
2. Literature review	7
3. Methods	8
4. Findings & results	9
4.1 Responses to lockdown: Familiarity & relief	9
4.2 Home-schooling, resources & responsibilities	10
4.3 School return	11
5. Conclusion & recommendations	12
5.1 Recommendations	12

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Summary

This report summarises qualitative research conducted in late 2020 with parents of autistic children and young people (CYP) attending mainstream schools in England, as well as some autistic CYP themselves. It aimed to understand how they experienced lockdown,¹ home-schooling, virtual learning and return to school. Findings indicate that conditions of lockdown such as disrupted schooling, reduced social contact and lack of spontaneity were already familiar to participant families. Retreating into the private sphere of the home came as a (partial) relief for many, providing respite from the intense parental labour involved in negotiating between CYP and schools. However, parents faced additional responsibilities to assist their children's access to schoolwork, and simultaneously lost vital support from families, support groups and therapies, which further exacerbated their marginalisation. Our findings lead us to argue that the pandemic has cast a harsh light on the ordinary workings of mainstream schools, which create and maintain 'spoiled identities' (Goffman, 1963) for many autistic students.

1 "Lockdown" here refers to England-wide restrictions that required people to stay at home to minimise the spread of Covid-19. We refer to the first period of lockdown as running from 26 March to 1 June 2020 (the beginning of phased reopening).

1. Introduction

This report summarises findings of research into how families of autistic children and young people (CYP) attending mainstream schools in England experienced and responded to home-schooling and lockdown. It presents the perspectives of 17 parents and six CYP about their educational experiences following the first government-imposed lockdown in the summer term of 2020. The research had the following objectives.

1. To understand how families of autistic CYP attending mainstream schools experienced lockdown, home-schooling and virtual learning.
2. To understand experiences of transition back to school after lockdown for families and autistic CYP.

The topic is of interest and importance for several reasons. First, autism is a developmental condition creating challenges for social interaction, social imagination, communication and in managing sensory challenges. Changes to routine are likely to generate disproportionate anxiety in autistic CYP, so adapting to lockdown, the blurring of home and school, and returning to school with additional infection-control measures may be challenging. Second, temporary changes to legal requirements for education and health care plans (EHCP) meant that previous levels of support for autistic CYP were no longer guaranteed (Department for Education, 2020). Third, lockdown may have brought some benefits for developing educational strategies for autistic CYP (Pavlopoulou et al., 2020). These three potentialities address our fourth rationale for this research: to expand the relatively small body of sociological research on autistic children and their families, generating knowledge and avenues for research on the relationships between parents, autistic CYP and mainstream schools.

2. Literature review

Research on the impact of the Covid-19 pandemic on families draws attention to its unequal impact on differently positioned families, highlighting the acute struggles of disadvantaged families (for example Crenna-Jennings, 2021; Cullinane & Montacute, 2020; Moss et al., 2020; Van Lancker & Parolin, 2020). International research suggests that families of children with special educational needs and disabilities (SEND), including autistic CYP, face unique challenges (Ameis et al., 2020; JCHR, 2020). The pandemic exacerbated the already poor mental and physical health experienced by many families (Althiabi, 2021), especially as they lost therapeutic interventions and adapted to changes in children's routines (NAS, 2020; Tokatly Latzer et al., 2021).

In the UK, research has drawn attention to the effects on autistic CYP of losing specialist support due to school closures and changes in councils' legal duties to support children (JCHR, 2020). In a survey of 4,232 responses by the National Autistic Society (2020), 65 per cent of respondents said that their autistic child struggled to engage with online schoolwork, and around half reported that their child's academic progress was suffering. Other research found that few schools provided individualised learning instructions, although if the child had an EHCP the school was more likely to provide better lockdown provision through regular communication and supplementary education materials (ACER, 2020).

However, some research shows that autistic children benefited during lockdown from decreased social pressure, reduced sensory challenges and more time spent on low-arousal activities and focused interests, with decreased anxiety levels for some (ACER, 2020; Pavlopoulou et al., 2020; Tokatly Latzer et al., 2021). Introducing Covid-safe practices in schools has potentially improved school experiences too, as autistic CYP have benefited from small-group bubbles and clear regulations (Autism Education Trust, 2020).

Research from before the pandemic shows how mainstream school can be a difficult environment for autistic CYP, who are at disproportionate risk of social isolation, and of being excluded and bullied, with resulting low academic performance (Humphrey & Symes, 2010; Roberts & Webster, 2020). Co-morbid

mental health difficulties, such as anxiety, may be triggered by the demands of mainstream schooling (Roberts and Webster, 2020). Autistic CYP are especially vulnerable to teacher misunderstanding/lack of training (Roberts & Simpson, 2016) as neurodiversity appears little understood (Farrugia, 2009; Francis, 2012; Gray, 1993, 2002; Lilley, 2013). This compounds families' stress, and they face extensive delays to diagnoses and support (BMA, 2020a, 2020b).

In understanding the school experiences of autistic CYP, 'stigma' is a useful concept. Stigma is a process whereby the bearer is discredited 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963, p. 3). Since autism is not immediately visible, CYP may, in order to avoid being 'discredited', respond to expectations that they be well-adjusted and fit in through various strategies of 'passing', 'covering' or 'withdrawing' (Goffman, 1963, p. 42). Such strategies of concealment, however, can internalise stigma: a powerful predictor of poor mental health for autistic individuals (Botha & Frost, 2020). Yet, while the sociological literature on stigma (for example Farrugia, 2009; Link & Phelan, 2014; Scambler, 2004; Tyler & Slater, 2018) recognises the value of focusing on experience of stigma, researchers also suggest that 'conceptual understandings of stigma inherited from Goffman [...] often side-line questions about where stigma is produced, by whom and for what purposes' (Tyler & Slater, 2018, p. 721). Instead, Tyler and Slater call for more attention to the macro-level structures and forces that create the conditions for its experience: the 'acts of institutions [...] within the broader political economy of neoliberal capitalist accumulation' (Tyler & Slater, 2018, p. 732). This draws our attention to the way in which the common-sense processes, organisations and assumptions in mainstream schools generate an environment of everyday discrimination that marginalises autistic CYP.

3. Methods

This small-scale qualitative study was guided by an experience-sensitive approach, using an ethos which avoids reproducing ‘deficit-based’ narratives about autism (Pavlopoulou et al., 2020; Todres et al., 2009). We established a parent advisory group of parents with autistic CYP to develop our research instruments and to work on emerging themes. We conducted the study in accordance with BERA’s (2018) ethical guidelines and with approval from UCL’s Institute of Education research ethics panel. To recruit participants, we distributed a survey through online parent groups in different regions of England, and by Twitter. We asked potential participants to submit brief demographic details and information about their child’s background, diagnosis and educational experiences. We received 25 responses, and from these secured 17 interviews with parents, with the majority of CYP aged over 10. Of those parents, most (10) answered ambivalently (‘yes and no’) to a question about whether they thought that their child’s educational needs had been met during lockdown. We provided respondents with written information in advance, and recorded semi-structured interviews with consent on Zoom throughout December 2020. We designed our interview schedule to encourage respondents to share their experiences and to find out how respondents assign meaning to them (Pavlopoulou & Dimitriou, 2019; Seidman, 2006).

We recruited six CYP (all White British, one female, five male) through their parents, and obtained their consent separately. We gave CYP written information, including a sample of key topics and invited them to record their thoughts, if preferred, through photography, drawing or modelling (although few chose to do so).

We hand-coded the data using thematic analysis (Braun & Clarke, 2019). We discussed initial findings with the parent advisory group, and refined these through further analysis of the data. Analysis will continue beyond the life of the project to draw out main findings in dialogue with theoretical resources.

Figure 3.1
Sample of parents

No. parents	Gender	Location (English region)	Ethnicity	Number & sex of autistic CYP
17	15 female; 2 male	7 London & south east 3 north west 2 north east 2 east of England 2 south west 1 West Midlands	10 White British 3 White Other 1 Black Caribbean/British 2 British South Asian 1 South American	23 school-aged autistic CYP (18 male; 5 female)

4. Findings & results

4.1 RESPONSES TO LOCKDOWN: FAMILIARITY & RELIEF

'We have a very structured life [...]. Like many families like ours, I can tell you what I'm doing in 46 Thursdays' time. There's no spontaneity [...]. I've got friends who don't have autistic children [...] they've been so badly affected by some aspects of the pandemic that haven't bothered us. Because you know we've always been quite isolated, we have always had to think carefully about what we do and how we do it and where we go.'

Vicky, White British, two autistic sons, Charlie, 12 & Ben, 15

A striking finding is the extent to which the pandemic's hallmarks of disrupted schooling, social isolation and lack of spontaneity simply continued an already stressful pattern of life for families of autistic children. Parents said that, because of the pandemic, other parents now experienced something of their everyday reality. Research by Twamley et al. (2021) documents the additional burden of 'Covid labour' for families, referring to required, pandemic-related tasks such as reviewing, planning mitigations, making decisions and adjusting to restrictions. Parents in our study, like Vicky (above), suggested that such tasks are not new, but familiar and necessary for navigating their children through risks to their wellbeing posed by a society that is often ill-equipped to accommodate autistic CYP. Our data shows that access to full mainstream education was already disrupted and fragmented for many autistic CYP. Before the pandemic, some had missed extended periods of schooling, some were excluded, while others were being educated in school, but outside the classroom. Some had pre-existing and severe mental health challenges, including anxiety about school attendance. Some teaching staff understood such school refusal as wilful non-compliance. This is a concern.

The pandemic – as a disruption of normality – shows how 'hierarchical social relations' (Link & Phelan, 2014, p. 25) both create and sustain autistic children's liminal position in mainstream schools. Autistic CYP and their families are vulnerable to stigma, especially as understanding and appreciation of neurodiversity vary. We plan to further explore

what one parent called 'a systematic lack' of recognition and response to autistic CYP's needs. This paper centres on our finding that the pandemic offered autistic CYP and their parents some relief from their marginal position in mainstream schooling and associated stressors. The majority of respondents, both CYP and parents, experienced the first lockdown (to varying degrees) as a release from the pressures of daily life.

'When lockdown first happened, you could see this bliss on his [Harry's] face. He wasn't asking hundreds of questions about when school was.'

Gosia, White Other, mother of Harry, 10

'In many ways there was a huge sense of relief when the pandemic came because we just didn't have to keep jollyng him along on a Sunday night anymore [...] Milo became a free spirit.'

Grace, White British, mother of Milo, 6

'The family walks at three o'clock every day, I did really like that.'

Louise, White British, mother of Jake, 9

CYP also appreciated the comfort and security of being at home (see Daniel's quote, below), and the freedom to engage with their special interests and outdoor activities. They enjoyed using fidget toys whenever they wanted to, or wearing soft pyjamas instead of sensory-challenging school uniforms. For some, not being at school meant that they did not have to deal with harsh attitudes from their peers.

'The really good thing about lockdown is that at least I feel comfortable, my family is safe and then I won't be too scared about the outside world [...] My parents, my favourite things I like to do [make me feel safe].'

Daniel, 12

However, there were negative emotional and physical effects of lockdown, especially early on, when going outside was restricted and schools were beginning to provide home-schooling materials.

Parents' ability to enjoy aspects of lockdown derived from a complex mixture of how CYP adapted, CYP's age and independence, the degree of support from school and other agencies, and the demands and security of their paid work. CYP did not uniformly enjoy isolation. While some young people did not miss, and may even have preferred, not having to be with peers, others found that difficult, and some lost confidence in their ability to socialise. Many could use technology like messenger apps to maintain relationships, but some struggled with anything as direct as Zoom, and lost contact with extended family, teachers and therapists. Gaming provided some CYP with a vital social link, as they were included in, and organised, online communities.

'So I think that he found safety in "I'm in my bedroom, I'm on my game – that's all I can cope, that's it" [...] so I think that his perception of friendships are through the game [...] on his game he has a group of people who report in to him, and he manages people, he runs his channel [...]'

Nicole, Black British, mother of Tom, 16

4.2 HOME-SCHOOLING, RESOURCES & RESPONSIBILITIES

In the first lockdown, the vast majority of CYP stayed at home. This was, in some cases, influenced by the absence of key staff and the inability of schools to provide continuity of support, especially as essential resources, like nurture rooms, were closed. The amount of school provision and support (such as work emailed home, direct contact with teachers) varied greatly. However, all parents noted that there was *little or no adaptation* to materials to make them suitable for their CYP. One parent, Grace, described the materials as 'unfathomable'; others, like Samantha (see below), were disappointed in the quality.

'We've literally printed off 120, 130 pages and then you know were just like "Right ok, how are we going to work through this?" And some of them were wrong [...] some of the answers were wrong.'

Samantha, White British, mother of Olivia, 11

Thus, most parents quickly gave up on home-schooling, or at least on their school's materials. Instead, they invested considerable time and effort into sourcing materials, planning timetables and developing approaches with which their children *would* engage (such as junk modelling: see Rory's model in figure 4.1).

The few CYP who did attend school largely benefited from small groups and were comfortable with the clear rules and routines for ensuring Covid safety. This enhanced the predictability and transparency of school life and expectations. Parents noted a similar reaction when the majority of children returned to school in September 2020.

Figure 4.1
Rory's junk model



Several families reported that lockdown delayed an already-lengthy diagnosis procedure and/or disrupted therapeutic interventions. Families also lost out as social groups and extracurricular activities stopped. With reduced professional and personal support, many parents were emotionally exhausted. Families' social, cultural and economic circumstances differed, and this affected the extent to which they managed during lockdown (for example, some could afford to buy resources for their CYP or could maintain networks through online support groups). The parents were highly knowledgeable about autism and experienced advocates for their children. However, they faced more 'Covidlabour' (Twamley et al., 2021) as they struggled to interpret rules and expectations (for example about home-schooling and outside exercise) which were formulated without reference to those with SEND.

Parents initially welcomed schools' messages about focusing on CYP's wellbeing rather than attainment. However, parents wrestled with concerns about educational outcomes, with lockdown seen as a further impediment to their

child's progress. Parents felt a heavy sense of responsibility for keeping their children engaged. For example, Beatriz (mother, South American) thought that teachers were ill-equipped to help her son Alejandro, so 'it falls on our shoulders to do something'. Despite all respondent-families having two parents living at home, there was a striking gender imbalance in terms of which parent home-schooled, which reflects a general trend (Yavorsky et al., 2021). Women took on the largest share, even when working (most were). The father was the main lockdown carer in only three families, and in one of those the mother was responsible for home-schooling while also working full time.

4.3 SCHOOL RETURN

Although pleased that schools could re-open, many parents felt anxious about their CYP returning to the familiar stresses. Indeed, one child was unable to return at all. Some CYP, like Bob aged 10, autistic with dyspraxia and Coffin-Siris syndrome, were nervous about 'all the noise [...] everyone shouting random stuff' and finding it 'hard to concentrate at school'. Most were, however, keen to return to face-to-face teaching, as some, like Matthew, 16, had felt 'left a bit behind' without the structure and interactions of school. Several CYP were looking forward to regaining contact with individuals who helped them. This echoed parents' appreciation of staff members who 'got' their child and who understood their child's sensory challenges or anticipated the impact of small changes in school routines. For example, Bob referred to the 'TA [who is] with me every step of the way, [who] helps me a lot' and Olivia, 11 (autistic with hypermobility and dyslexia) referred to 'the teacher who gets me, she knows I've got autism and she helps a lot in PE [...] she's really nice to me'. Without that support, Olivia missed school on PE days, as she found changing clothes, close physical contact with others and physical activities challenging. Some CYP found that during the pandemic, staff sickness and changes in timetables meant that they lost 'the teacher who helps me the most' (Rory, 10, a sense shared by Ben, 15).

'It [class bubble] means that other classes can't be mean to me. It's better to have break just with your class [...] and stick with most of the people that you actually know'.

Rory, 10

Such understanding and insight on the part of schools was far from widespread or integrated. For example, Olivia noted a lack of understanding from some teachers although she'd been given special permission not to wear a mask. This not only made her feel 'weird' as the only child in that position, but it was also 'annoying' that some teachers were not aware of her condition and would reprimand her, despite her wearing a badge to indicate her exemption.

CYP referred to the benefits of Covid safety measures, for example, having to mix with those from their own classes only (see Rory, 10). However, CYP wished that *everyone* at school was 'kind' or 'nice' to them like the people in their support teams.

5. Conclusion & recommendations

Contrary to much of the emerging research on the pandemic and its effects on families, we found that lockdown in the private sphere of the home came as a (partial) relief to respondents. These parents work hard, in usual circumstances, to negotiate between their CYP and schools. Many parents of neurotypical CYP also struggled with the demands of home-schooling, but there was an additional, significant (and often gendered) burden on parents in helping their autistic CYP to access the school curriculum. Direct contact with teachers was infrequent, and families also lost other sources of support. Although lockdown offered a release from the ‘daily indignities’ (Link & Phelan, 2014, p. 30) of everyday school life, the lack of suitable educational materials and the increased isolation from support indicate the marginalisation of autistic CYP. The pandemic has cast a harsh light on the ordinary workings of mainstream schools, which create and maintain ‘spoiled identities’ (Goffman, 1963) for many autistic students.

5.1 RECOMMENDATIONS

We understand ‘marginalisation’ as the outcome of organisational and structural assumptions about how students should be and behave rather than discrimination against individual autistic CYP. Provision for autistic CYP can be improved if teachers are given time, space and resources to reflect on these assumptions. We recommend that schools take the following steps.

- Reinstatement of support such as nurture spaces – often seen as dispensable during the pandemic – or provide alternative adapted provision.
 - Develop wider acceptance of autism, and recognise the mental health strains caused by ‘normal’ school environments and expectations of behaviour. Our data suggests that teachers may know a little about autism, but many have normative expectations about how schools ‘should’ run, and about how children ‘should’ behave.
 - Develop a whole-school support strategy. Rather than seeing autism awareness (for example, of sensory challenges and the impact of changed routines) as the purview and responsibility of one or two staff members who ‘get’ autistic CYP, complete inclusion requires this to extend to a whole-school culture of knowledge and action involving students as well as teaching and non-teaching staff.
- Review the transparency of school expectations: incorporating the much-appreciated transparency of Covid safety measures into everyday school provision would benefit autistic children.
 - Review how home learning tasks can be made accessible for those with SEND, especially when online learning is required. The difficulties in accessing schoolwork experienced by our CYP participants indicates that such adjustments are not routine.

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