

Ashworth, E, Bray, L, Alghrani, A and Kirkby, J

'Vulnerable and abandoned' - The impact of the COVID-19 pandemic on education, health and social care provision for children with SEND: Children and parents' perspectives

<https://researchonline.ljmu.ac.uk/id/eprint/20088/>

Article

Citation (please note it is advisable to refer to the publisher's version if you intend to cite from this work)

Ashworth, E ORCID logoORCID: <https://orcid.org/0000-0002-5279-4514>, Bray, L, Alghrani, A and Kirkby, J (2023) 'Vulnerable and abandoned' - The impact of the COVID-19 pandemic on education, health and social care provision for children with SEND: Children and parents' perspectives.

LJMU has developed **LJMU Research Online** for users to access the research output of the University more effectively. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LJMU Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

The version presented here may differ from the published version or from the version of the record. Please see the repository URL above for details on accessing the published version and note that access may require a subscription.

For more information please contact researchonline@ljmu.ac.uk

‘Vulnerable and abandoned’—The impact of the COVID-19 pandemic on education, health and social care provision for children with SEND: Children and parents’ perspectives

Emma Ashworth¹  | Lucy Bray²  | Amel Alghrani³  | Joanna Kirkby¹

¹School of Psychology, Liverpool John Moores University, Liverpool, UK

²Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, UK

³School of Law and Social Justice, University of Liverpool, Liverpool, UK

Correspondence

Emma Ashworth, School of Psychology, Liverpool John Moores University, Byrom Street, Liverpool, L3 3AF, UK.
Email: e.l.ashworth@ljmu.ac.uk

Funding information

National Institute for Health Research

Abstract

This study aimed to understand children with special educational needs and disabilities’ (SEND) and their parents/carers’ experiences of the pandemic in the UK, using mixed-method surveys ($n = 893$ parents, 55 children) and qualitative interviews ($n = 10$ parents, 4 children). Descriptive statistical analyses and thematic analysis were utilised. Findings suggest that the needs and rights of children with SEND were not given due consideration during the pandemic, resulting in a decline in mental health, and their social, emotional, academic and physical development. Restrictions were reported as compounding and exacerbating the existing challenges faced by children with SEND in gaining equitable access to services.

KEYWORDS

children, COVID-19, education, health and social care, parents/carers, special educational needs and disabilities

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2023 The Authors. *Children & Society* published by National Children’s Bureau and John Wiley & Sons Ltd.

INTRODUCTION

In March 2020, the first national lockdown was implemented in England to slow the spread of the severe acute respiratory syndrome-coronavirus-2 (SARS-CoV-2). Those who were not key workers were told to stay at home, not mix with other households and to socially distance in public. Schools were closed except for vulnerable children and those of key workers. Another national lockdown occurred from 6 January until 29 March 2021, when schools were again closed for most pupils and working from home was advised.

Children were a group particularly adversely affected by the restrictions, with them experiencing many changes at home and in school (Ashworth, Hunt, et al., 2022; Bray et al., 2021). Many children experienced disruptions to their friendships, sleep and activity routines, found home learning overwhelming and struggled to keep up with schoolwork (e.g. Ashworth, Putwain, et al., 2022; Morse et al., 2022). Parents also reported that their children missed their friends and lacked social interaction (Morse et al., 2022). While many children demonstrated resilience, some experienced an especially difficult time and there is mounting global evidence of the adverse effects on children's mental health (e.g. Waite et al., 2022).

However, children with special educational needs and disabilities (SEND) have been overlooked in extant COVID-19-related research, despite the fact that they are some of the most vulnerable in our education system (Byrne, 2020). Prior to the pandemic, there were already severe disparities and flaws in education, health and social care provision for children with SEND (Alghrani & Byrne, 2020); chronically underfunded by an estimated £1.5 billion (Disabled Children's Partnership, 2018), SEND support services were threadbare and diminished (O'Hagan & Kingdom, 2020). In addition, the system for acquiring SEND support has been exemplified by 'confusion and at times unlawful practice, bureaucratic nightmares, buck-passing, and a lack of accountability, strained resources and adversarial experiences' (House of Commons Education Committee, 2019, p. 3).

These difficulties were exacerbated by the pandemic. Evidence indicates that the education of children with SEND was adversely affected by pandemic-related legislative changes (Alghrani & Byrne, 2020) and special schools faced extreme difficulties as a result of having to run at a severely limited capacity (Skipp et al., 2021). In terms of health care, essential appointments and assessments were rescheduled or cancelled, meaning there was insufficient support for children with SEND and their families when they needed it most (Council for Disabled Children, 2021). A national survey of parents of seriously ill or disabled children found that in March 2020, 65% ($n = 2267$) of parents were receiving a decreased level of vital support for their child (including educational psychologists, speech and language therapists, and Child and Adolescent Mental Health Services [CAMHS]). Through 'interim visits' to children's services, The Care Quality Commission (CQC) and OFSTED (2021) found that some children had been left immobile and in pain due to the cessation of physiotherapy, and some were unable to communicate fully due to a lack of speech and language therapy.

However, children with SEND remain underrepresented in the growing body of research on the pandemic, which in many cases has been quantitative in nature, or has relied on proxy reports of children's experiences. As such, this study aimed to gain an understanding of children with SEND and their parents/carers' experiences of the pandemic and associated restrictions in terms of education, health and social care. This paper reports on the findings of a distinct phase (phase 2) of a larger study consisting of three phases: a rapid review of the evidence (phase 1), mixed-method surveys and semi-structured qualitative interviews (phase 2) and policy priority setting workshops (phase 3). These research findings are particularly timely due to the current

reform of SEND provision in England, and the importance of including the voices of children with SEND and their families in any legislative amendments.

We aimed to (1) explore children with SEND and their parents/carers' experiences of accessing education, health and social care services during the pandemic and (2) understand the perceived impacts of the pandemic and associated lockdowns on the development and wellbeing of these children. In the present study, we use the term 'SEND' to refer to children with special educational needs (SEN) and/or disabilities, in line with the UK's 2014 Children and Families Act (CFA, 2014). In UK legislation, children with SEND typically fall into one of four broad 'areas of need': communication and interaction; cognition and learning; social, emotional and mental health difficulties; and sensory and/or physical needs. Based on their level of need, children can either be in receipt of SEN support (i.e. provision and adjustments in school) or have an Education, Health and Care (EHC) Plan (a legal document covering provision that the child is entitled to). For this study, we included children with an SEN across the areas of need, children with a disability, those in receipt of SEN support and those with EHC Plans, as well as those awaiting diagnosis.

METHOD

Design

We used a mixed-methods sequential explanatory Quant → Qual (Creswell & Plano-Clark, 2003) design to learn from children with SEND and their parents/carers using online surveys and qualitative interviews. The study was funded by the National Institute for Health Research (NIHR202718). Ethical approval was provided by the Institution's Research Ethics Committee (21/PSY/020, 21/PSY/026).

Public involvement and engagement

The team consulted with children and parents to inform the design of the study. We attended an online youth forum with four young people who advised on survey and interview design and consulted with three children with SEND who helped develop the surveys and information sheets. Two parents advised on the parent surveys, information sheets, and recruitment methods. All suggestions were adopted. The study steering committee, which comprised a range of professionals working within SEND services, offered invaluable guidance throughout the project.

Data collection

Online surveys were administered through SurveyMonkey between June and August 2021. The parent/carer survey included closed- and open-text questions grouped into sections (see [Supporting Information](#)). The surveys began with opt-in consent for parents/carers, followed by demographic questions about themselves and their child(ren), and then questions relating to their experiences of various elements of SEND provision. At the end of the parent/carers section, they could choose to provide consent for their child(ren) to take part in a separate survey, or to end the survey. The survey for children was designed to foreground their abilities, encouraging participants to 'draw, write and label' (Bray et al., 2021) good and challenging things about the

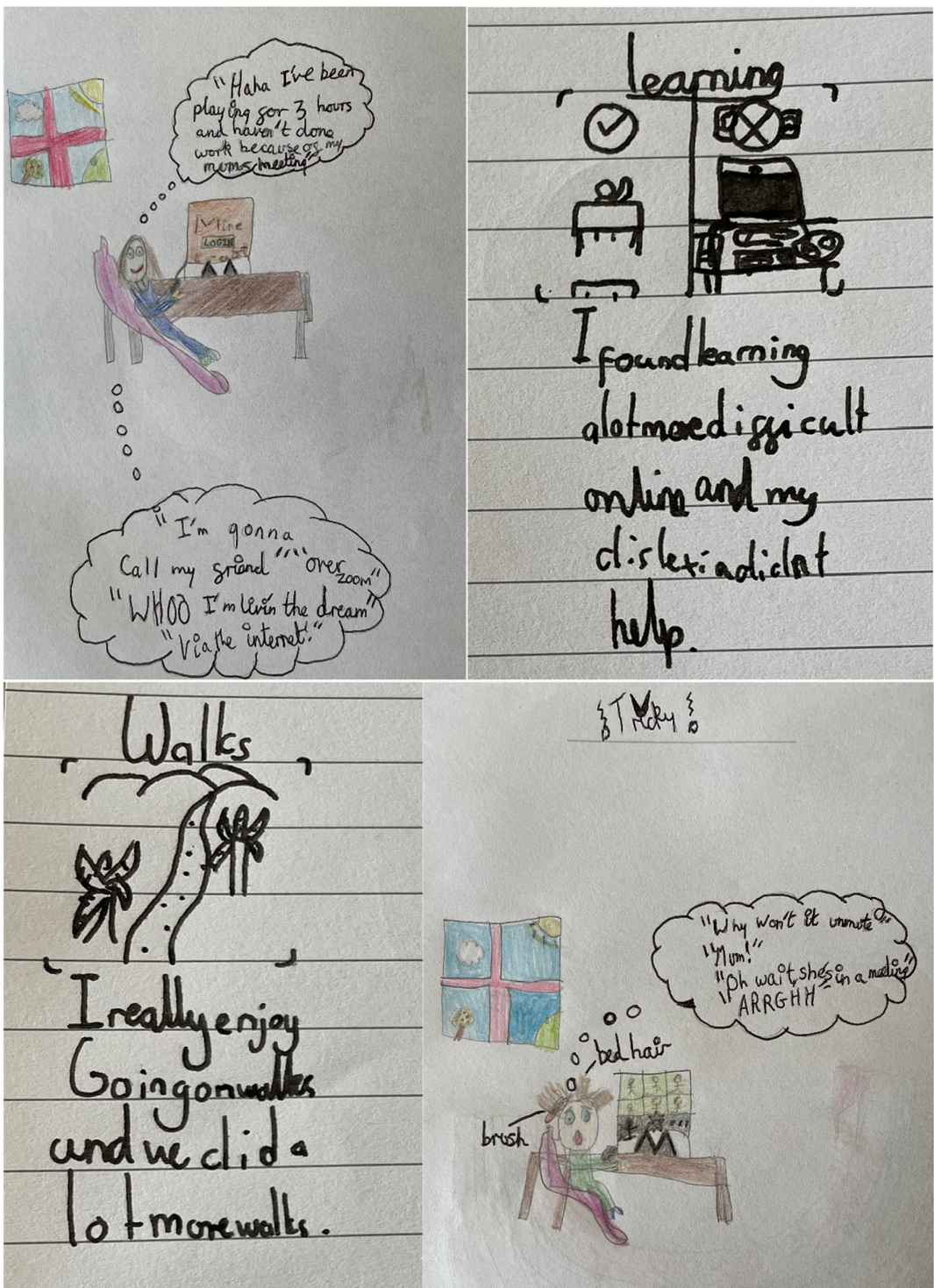


FIGURE 1 Children's submitted drawings of their lockdown experiences.

pandemic and then attach their pictures to the survey (Figure 1). The questions could also be answered by selecting emojis or typing. While we recognise that the use of online surveys may have excluded some children with SEND from participating, our methodological choices were shaped by Public Health restrictions at the time. We tried to mitigate this limitation by involving children in helping us to design the survey as well as using other methods in other phases of the study.

Qualitative semi-structured interviews were used to gain insight into the perceived impacts and experiences of children with SEND and their parents/carers. Topic guides were developed, encompassing questions and prompts/probes relating to experiences of the pandemic and associated restrictions (e.g. 'what has the COVID-19 pandemic and the lockdowns been like for your child?'). Interviews were conducted via online platforms. Activity books (see [Supporting Information](#)) were sent to children before their interviews, which included information about questions that would be asked and places for them to note down ideas they wanted to share. We also offered short 'say hello' meetings with children prior to the interview, to help us ascertain communication preferences and styles, and any technology needed to support the interview. Interviews were then adapted accordingly; for instance, one child chose to write their answers in advance and send them to the research team.

Participants and recruitment

We recruited participants for the online survey via social media and through direct contact with relevant organisations/networks. Parents were invited to take part if their child(ren) had any SEND and were aged between 5 and 16 years. Parents were asked to self-select at the end of the survey if they were willing to share their views in a follow-up interview. Parents who registered an interest were contacted via email with an invitation to participate (for themselves and/or their children). Interviews were conducted between August and September 2021.

Fifty-five children with SEND aged 5–16 years and 893 parents completed the survey. Parents and their children were located across the UK, and 91% ($n = 767$) of parents reported that their child had a formal/official diagnosis of a special educational need or disability. From the choices available to them, 67% ($n = 600$) of parents told us that their child had communication and interaction needs, 52% ($n = 465$) had cognition and learning needs, 42% ($n = 379$) had social, emotional and mental health needs, and 34% ($n = 306$) had sensory and/or physical needs. Parents could select all that applied.

Four children aged 8–14 (all male) with SEND (including autism, ADHD, sensory impairments, specific learning difficulties and mental health needs) took part in an interview. The interviews lasted between 9 and 15 min. Ten parents (all female) of children with SEND (including autism, ADHD, sensory needs, mental health needs, genetic conditions and specific learning difficulties) participated in an interview. The interviews lasted between 18 and 55 min.

Analysis

Descriptive statistical analyses of the quantitative survey data were conducted in SPSS v27. Analysis of the qualitative open-text survey responses and interviews were conducted separately and in accordance with Braun and Clarke's (2021) reflexive thematic analysis. Data were analysed inductively. Whilst the broad topics of health, education and wellbeing framed some of the questions we asked, the accounts also included many broader aspects of daily

life. Firstly, the interviews were transcribed using the Otter programme (www.otter.ai), and open-text responses were extracted from the survey and compiled. J.K. then began reading and re-reading the transcripts/responses, familiarising herself with the data. Data were then coded in NVivo. Codes were then collated into potential themes in an iterative process, returning to the data and relabelling codes to develop the themes. Potential themes were shared with the other researchers (E.A., L.B., A.A.) for feedback, and the developing themes were further refined and defined. Further analysis then occurred via the process of writing (Smith et al., 2015), before being discussed and further developed within the research team. Analysis was collaborative and we acknowledged the multiple world (academics, parents, carers) and disciplinary (health, psychology, law) views of the researchers involved, which may have shaped interpretation.

FINDINGS

Five themes were identified: the interruption to play, recreation and social interaction; deteriorating social-emotional wellbeing and mental health; inaccessible education and learning; perceived cessation of health and social care provision; and a lack of respite and support for parents. Relevant quantitative data related to each theme is presented alongside the qualitative data, in line with the explanatory mixed-methods design.

Participant identifiers alongside quotes are made up of letters signifying whether the quote is from a parent/carers (P) or a child (C), followed by unique numbers for each participant, and letters indicating whether their response is from the survey (sur) or an interview (int).

‘I was lonely. I could not use Zoom like other children’: The interruption to play, recreation and social interaction

Parents and children highlighted key issues around the isolation that resulted from COVID-19 lockdowns, both in terms of the lack of access to recreation and access to social support. Resources that were essential to children with SEND's physical health were removed, and the technology that neurotypical children used to stay in touch with their friends was not always accessible for children with SEND.

Even the parks were shut

Whilst ‘not going out the house for weeks’ (P103sur) was the experience of lockdown for many families, the lockdown was even more restrictive for the 10% ($n = 83$) of children who did not go ‘anywhere due to shielding’ (P195sur). As the majority of children's playgrounds were closed during the first lockdown, 78% ($n = 435$) of parents reported that their child with SEND had less access to parks and playgrounds in lockdown than pre-pandemic.

One child told us: ‘I was at home for a long time. I got very bored not even the parks were open’ (C18sur). Many parents spoke about how challenging this was: ‘children had parks close at a time when they needed them the most, and this was not done based on evidence of risk ... The whole thing is a disgrace and has had very little thought for our children’ (P215sur). One

parent described that even SEND-specific playgrounds were closed: 'we had a key to a secure park which would have been a safe place for my child to exercise as it was built for children with additional needs. This was closed until May 2021' (P773sur). The cessation of play and recreation opportunities was problematic for children with SEND, as they lost opportunities to fulfil sensory (vestibular) needs for movement: 'my whole house is like Fort Knox to try and keep them safe ... making sure they can hang, climb, run, jump, spin safely. Because they need that sensory input to help them regulate, and they're not getting it' (P1int).

Play facilities, clubs, and activities usually provide an opportunity for children with SEND to socialise and make friends, and act as a 'bit of a lifeline for many parents' (P8int). One parent described how closures of these impacted their child:

It was a big problem for [her] because she learns from her peers how to act socially. She loved it ... when we were doing a Zoom call. To see all her friends, she got very excited. But having the lack of speech or confidence to speak, she didn't really speak to anybody, but she saw them, and she listened. (P9int)

Feeling abandoned by friends

Seventy-one percent ($n=198$) of parents reported that their child's social skills got worse, and 69% ($n=407$) reported that their child had weaker friendships following the pandemic. Multiple children reported 'I missed my friends' (C22sur), and many parents reported that their children had 'no contact with friends. It was awful' (P217sur). Many also described how the restrictions exacerbated pre-existing difficulties in forming friendships: 'his ability to make friendships has become weaker. We spent years building this up and now he has become distant again although he craves it so much' (P427sur). One parent described how their child had struggled to maintain friendships when 'her only 2 friends have not maintained contact with her ... She feels abandoned, isolated and like she has nobody'. (P67sur). Many stated that restrictions left their child lonely and in 'extreme isolation' (P299sur), which negatively impacted their child's development: 'isolation is terrible for a child with autism. During the first lockdown he regressed to nursery behaviours, including socially' (P276sur).

Several parents highlighted how the lack of social interaction led to their child's communication skills regressing 'back to baby speak' (P1int). Many spoke about difficulties due to mask-wearing and many interactions moving online: 'challenges of online/virtual socialising for a child who cannot talk or type - very difficult to use sign online' (P743sur). These challenges were described by a child who is blind: 'I was lonely. I could not use Zoom like other children. I cannot see, and the sound is not enough. I could not follow the conversation. I really need to touch people to know what they are paying attention to' (CYP4int).

However, the experience of online communication was not the same for all participants. Several parents spoke about their child finding online socialising easier than face-to-face: 'he has better social skills online ... so has had less falling outs or misunderstandings due to his social communication difficulties' (P851sur). For some, the pandemic provided respite from the stress associated with social interactions, with some children saying they enjoyed 'less forced socialising' (CYP30sur): 'I get to be antisocial with no repercussions' (CYP35sur). Furthermore, the pandemic restrictions also afforded some autistic children a break from 'masking' and gave them a chance to 'be able to be me' (CYP46sur).

‘The anger and violence escalated a lot’: Deteriorating social–emotional wellbeing and mental health

Participants described children with SEND's mental health deteriorating during the lockdowns, with children feeling confused, scared, frightened, and at times suicidal. Parents felt that this was exacerbated by the lack of accessible support. In turn, parents described how their own mental health was negatively affected.

Feeling confused and scared

Children with SEND were asked to indicate how they felt about COVID-19 and the lockdowns, 46% ($n=22$) chose an ‘unhappy’, ‘crying’ or ‘angry’ emoji, 35% ($n=17$) chose the ‘in the middle’ emoji (a face which was neither smiling nor frowning) and 18% ($n=9$) chose a ‘happy’ or ‘excited’ emoji (mainly because they liked being at home). Children described a range of negative emotions including feeling ‘lonely’ (CYP4int), ‘sad and bored, every day the same’ (CYP44sur) because they had ‘no friends left. Anxiety. Suicidal thoughts’ (CYP15sur).

Several children described the pandemic as ‘scary’ (CYP12sur) and ‘frightening’ (CYP55sur) and explained they ‘worried thinking a family member will catch covid and die’ (CYP12sur). Parents reported that many autistic children experienced anxiety and stress due to the uncertainty and lack of routine: ‘constantly changing routines, being away from school for long periods of time’ (P714sur), which in some cases ‘caused large meltdowns’ (P785sur). Parents described ‘dealing with spiralling mental health issues’ (P50sur) with their child, for instance: ‘being very sad, saying he didn’t want to live the next day. He stopped eating ... and we ended up in A&E because he wanted to die ... He didn’t understand what was happening’ (P6int). Some parents described very challenging circumstances:

He went through a stage he had night terrors every night ... It was very difficult, and [he] had some very dark times with his violent behaviour and anxiety that was mostly aimed at me when I got home ... [which] escalated a lot, so I had a black eye, and we had a lot of breakages at home ... because I suppose he couldn’t vent his stress anywhere else. (P2int)

Participants described how it was difficult coming out of lockdown as ‘all the rules had changed. Not everything is open, or it isn’t the same. It’s confusing’ (CYP6sur). This led to some children feeling ‘scared of going out because everything had changed’ (CYP16sur) and ‘anxiety about seeing people after so long’ (CYP27sur), and others found it hard being away from their parents when back at school: ‘missing my mum’ (CYP8sur). Children explained they also had ‘fear of catching coronavirus’ (CYP49sur) and were ‘worrying things would go back to lockdown’ (CYP22sur). Many parents felt their child ‘could not cope’ (P157sur) with reintegrating back into social situations: ‘refusing to go out and fearful of public places’ (P243sur).

It would have to have got really bad to get any support

Despite many parents (65%; $n=179$) reporting that their child’s mental health was worse during the pandemic, they struggled to access support. In terms of CAMHS, 24% ($n=55$) reported

that their child was receiving face-to-face support before the pandemic, but during the first lockdown, this dropped to 5% ($n=9$). In some cases, CAMHS support was reported as moving online (15%; $n=28$). When asked what support had been available from CAMHS for their child, one parent described how they had been 'referred through to them [CAMHS] ... three times ... but each time we have been rejected..., we never quite met the threshold ... I don't know how bad it would have to have got to actually get support' (P2int).

One parent told us their child only got support from CAMHS after they reached crisis point: 'referrals to CAMHS were not accepted, we were offered much more once an inpatient in hospital after reaching crisis point' (P797sur). Another parent suggested that mental health support should be offered earlier: 'we need healthcare to understand what it's like to be autistic, and to actually offer these services earlier than when kids are self-harming ... The money isn't put in place' (P6int). As well as reduced access to CAMHS, access to mental health support in school (e.g. counselling) was also reported by parents as greatly reduced, dropping from 27% ($n=136$) before the pandemic to 3% ($n=14$) during the first lockdown.

Most parents (67%; $n=582$) identified that their own mental health had 'got worse' over the pandemic. Several spoke about struggling with their mental health, describing it as 'chaos' (p5int) and explaining how the pressure had led to them experiencing a breakdown: 'I've had a breakdown because of it all because you just feel like you've failed your child' (P6int). Parents spoke about the need for more 'mental health and wellbeing services and respite for the parents, and siblings. If our tanks are running empty then it is very difficult to manage family life' (P613sur).

'It was just hell on earth': Inaccessible education and learning

Education offered to children with SEND was considered to be inaccessible for two key reasons: firstly, parents reported that they often could not secure a place in school for their child, despite them meeting the criteria, and secondly, the educational resources that were provided for children who were learning remotely were often inappropriate and inaccessible, and lessons were not differentiated appropriately.

Fighting for a place in school

During national lockdowns in the UK, schools were closed to all pupils except those deemed 'vulnerable' or children of keyworkers. The government definition of vulnerable included children with an EHC Plan. Although 61% ($n=518$) of parents reported that their child did have an EHC Plan, 89% ($n=655$) reported that their child was not given access to full-time face-to-face education. Of those, 20% ($n=120$) reported that the school had advised that their child should stay at home, and 20% ($n=121$) reported that they were told by the school that their child could not attend. Sometimes, this was due to staff shortages: 'we had a bit of a battle, the school didn't want to have him back during the lockdown because they said they couldn't staff it, but in the end a social worker contacted the educational board ... in the end, it was done that he was on a reduced timetable' (P2int). For others, the lack of a school place was deemed to be due to the complexity of their child's needs:

Because he is more complex, the rest of the children in his class ... can walk and eat and do other things ... because he needs a lot more support, she decided that he would be the one that wouldn't be in school ... I emailed back to say he's got a legal right to be in school, but then she didn't get back to me after that. (P4int)

Children shared mixed views about not attending school, one child chose the 'very happy' emoji 'because I didn't have to go to school' (CYP25sur), and others said that a good thing about the pandemic was having 'no school' (CYP24sur). Conversely, several children mentioned that they 'hated not being in school' (CYP6sur). During this time, parents/carers also reported that their child had little or no direct contact with school staff (38%, $n = 339$):

The teacher ... didn't really want to engage, he was looking after the majority of the classroom and seemed to ignore [her] ... We did feel very let down by the school's provision for her and her needs. So as a Mum, I just felt, again, just having the child with a disability and coming at the back of the line. (P9int)

Struggling to access remote learning

Children with SEND who were not in school during the lockdowns were usually offered remote learning; however, when asked what the difficult things had been about the pandemic, children answered: 'learning—it was difficult with my dyslexia' (CYP3sur), 'trying to do online school' (CYP4sur) and 'not having a proper teacher to help me' (CYP9sur). Many parents/carers (46%; $n = 261$) also reported that remote learning was ineffective in meeting their child's needs, as it was not differentiated or accessible: 'they used set work, just standard work' (P10int) and there was 'no scope for individual support or ability for teacher to help individuals' (P412sur). One parent added:

She could not access live lessons because she has hearing impairment & relies on lip reading - the school would not provide closed-captions on Zoom - had to stick to a timetable and it was intense, a lot of information given all at the same time visually, auditory to process. (P577sur)

Many parents also noted how difficult it was for some children with SEND to sit at a screen all day: 'for a child with ADHD to be expected to sit in one room staring at a laptop for hours and hours on end is a very difficult task' (P594sur). Several parents explained they had initially tried to implement remote learning, but this had not lasted:

There is absolutely no way we could home-school. We tried it during the periods of isolation, and it was just hell on earth ... As soon as my attention is diverted to one [child] trying to do the set work, the other is just bouncing off the walls, running across the furniture ... In the end, I'll be honest I abandoned it ... Our kids, they do schoolwork at school, and home is for home, and they just can't cope with the concept that the two mix. (P1int)

Many parents (89%, $n = 397$) reported that their child had not been provided with the SEND-specific technology they needed to engage in their learning (e.g. accessible/assistive software and

applications such as screen readers, Picture Exchange Communication Systems). Furthermore, the online learning systems did not meet the learning needs of pupils with SEND:

I think they set up like a Teams thing once a week, but he can't access that. Technology ... would be a big massive barrier. They'd expect him to know what his email and password was, he doesn't even know what an email is ... He didn't really get anything sent for him ... until I had a call with a teacher and he sent me some like colouring sheets, and stuff like that just wasn't really helpful. (P8int)

Parents described children with SEND as experiencing 'lost learning' over the pandemic, with 69% ($n = 509$) reporting that the national lockdowns had negatively impacted their child's education. One child explained: 'I don't think I learnt much' (CYP2int). However, this was not the same for all children with SEND, with a minority stating: 'home learning is easier than school learning' (CYP38sur), and some children flourished: 'it was a good way for [him] to learn. A relaxed, quiet atmosphere without distractions or other students. He could work at his own pace and move on to his own thing when he was done. He liked the autonomy' (P37sur), and 'because she was sat with no distractions and with an adult who could provide 1-to-1 support at the moment she needed it, she moved from "low average" to "top of the class"' (P27sur).

Working at their own pace meant children 'could take sensory breaks' (P345sur), 'repeat activities and lessons as often as [they] wished' (P743sur) and 'pause videos to process things or refer back to' (P174sur). Remote learning also worked well for some children as it gave them 'flexibility with when it could be done' (P21sur) and 'flexibility to explore [my] child's interests' (P358sur).

Parents commonly described poor and reduced communication and support from education providers and Local Authorities about their child's learning needs. Many reported that they had little or no contact with the school whilst their child was learning remotely (58%; $n = 335$), and only 23% ($n = 128$) were happy with the support offered to them:

There was no communication or no support ... Nobody would contact me and say, "how are you getting on? Is anything we can do?" I even said, "can you send homework in a paper format? So at least ... she can still do something." But no, they wouldn't do that. Point blank refused. (P5int)

'The radio silence and closed-door policy from professionals was frightening': Perceived cessation of health and social care provision

Parents described how their children could not access the essential services that they needed to maintain their physical health during lockdowns. They also highlighted how the provision of key services took a long time to be re-instated.

During the pandemic, much of the health and social care support previously available was reported by parents as completely stopping. Some parents were told this was due to the 'redeployment' (P56sur) of professionals to COVID-19-related duties. Access to hospital appointments and key therapies were reported as greatly reduced, with access to hospital appointments dropping from 55% ($n = 127$) before the pandemic to 10% ($n = 18$) during the first lockdown, speech and language therapy dropping from 41% ($n = 88$) to 1% ($n = 2$), occupational therapy dropping from 35% ($n = 77$) to 2% ($n = 3$), physiotherapy dropping from 32% ($n = 66$) to 2% ($n = 3$) and diagnostic and

referral pathway appointments dropping from 26% ($n = 55$) to 4% ($n = 7$). Children who usually received healthcare in school could no longer receive this 'as he could not visit school' (P154sur). Furthermore, healthcare appointments had still not resumed at the time of data collection (June–August 2021), despite schools having re-opened to all pupils:

We were receiving Occupational Therapy pre-lockdown, but that obviously stopped, my son was receiving Psychology, but that obviously stopped ... The waiting lists for the therapists are all very long. I don't know when they're going to be back up and running. Even the therapists they were seeing are too busy to take them back on again. (P1int)

Another parent explained how the cessation of healthcare appointments meant they received no support: 'it was frustrating because everything stopped, I mean literally everything. We've not seen as many professionals ... It took away any kind of support that there was' (P7int). One parent how 'the radio silence and closed-door policy from professionals was frightening' (P427sur). Parents had to 'fight' to get their child's healthcare needs met, which had a notable impact on parents' wellbeing: 'you do it because you have to ... what choice do you have? You do anything for your child don't you? All the fighting, like fighting for equipment, fighting for everything that you need. It's exhausting' (P4int).

Parents described that although some appointments went ahead online, some children were 'unable to take part online' (P603sur). However, for some, online appointments worked well: 'virtual hospital appointments (Attend Anywhere) are a good development – hope it continues' (P312sur), as 'getting him to a hospital was traumatic for everyone' (P88sur).

When asked: 'Was there anything that supported you as a family over COVID?' one parent responded: 'no is the simple answer ... this is what brought everything on to its knees ... that was the difficulty, even if we would have just been validated and just checked on once a week, just a phone call ... we were very, very alone' (P6int).

'As a parent I am at rock bottom': A lack of respite and support for parents

Finally, the impact of the COVID-19 lockdown on children with SEND's wellbeing, and lack of access to appropriate services and resources, resulted in parents highlighting a sharp decline in their own mental health and wellbeing.

Parents described high levels of stress and difficulty and a lack of support, with reported access to support groups dropping from 30% ($n = 62$) before the pandemic to 2% ($n = 4$) during the first lockdown, while access to respite and short breaks was greatly reduced from 29% ($n = 64$) to 3% ($n = 6$). Parents/carers explained there was 'no respite at all. I am now at burn out' (P805sur). One parent described:

[The pandemic] has left me scarred, scared and broken ... the rules forbade us from any support with care, any respite, or any access to their normal activities, including schooling. I was left to deal with it all on my own. I was bitten, kicked, punched and pulled almost every day because of my children's frustration and anxieties. I had to deal with my own mental health ... and also cope with my paid job and care for my three kids, without any help or support from children's services or the LA ... It has been a traumatic experience which has had a massive impact on our mental health and has made us feel vulnerable and abandoned. (P726sur)

Many of the parents shared accounts of feeling 'at rock bottom' (P432sur) and how a lack of respite impacted family members' ability to support their child: 'when we suffer, he suffers more' (P6int). During the pandemic, school closures meant parents had no break from their caring responsibilities:

I think the whole thing is challenging because having a child as complex as [him] is hard and challenging anyway. Then you add in the fact that you've got less support because of [not going to] school. You don't get any respite because that's my only respite ... It's exhausting. (P4int)

Parents reported feeling 'blamed' and judged when they asked professionals for help: 'there is much more of a blame culture going on, as in blame the parents. And a lot of parents do feel like we're being very judged when we asked for help' (P1int).

Whilst many families had to face new challenges in juggling work and childcare, this was exacerbated for parents of children with SEND, whose children often needed higher levels of support and care:

A lot of [my husband's] work is over the phone and all the meetings via Zoom ... when you have [our son] kicking off and swearing in the background, it can become very stressful ... He then started smoking again and things like that, the impact it had on him (P2int).

One mother had made the decision to stop working during the pandemic due to difficulties balancing work and childcare: 'I had to make the decision to give up my 25-year career ... Trying to work from home with the children ... I couldn't do it competently. I've ended up having to take the decision that trying to work doesn't work for my family' (P1int).

DISCUSSION

This mixed-methods study addresses gaps in understanding around the experiences and perceptions of children with SEND and their parents/carers regarding the pandemic and restrictions. The findings highlight how the pandemic exposed and exacerbated already stark inequalities and weaknesses in SEND provision, leading to short- and long-term impacts for children with SEND. While circumstances during the pandemic were unprecedented, many children with SEND were prevented from being able to live their lives, maintain their health and education, and be a part of the community, as outlined in Article 23 of the United Nations Convention on the Rights of the Child ([UNCRC], United Nations, 1989).

The social isolation of children with SEND has been well documented prior to COVID-19, with school holidays being especially vulnerable times (Knight et al., 2009). The current study suggests that pandemic restrictions further isolated children with SEND, as many spent long periods of time away from school. Furthermore, while most of the world was 'going online', many children with SEND struggled to communicate virtually. This is concerning as the absence of friendships has been shown to negatively impact children's self-esteem, as well as increase anxiety, depression and social withdrawal (Berndt, 2004). However, these impacts on mental health may not be the same for all children; the meaning of friendship and social interaction may look different for some

children with SEND. For example, the pandemic restrictions gave some children welcome relief from 'forced' socialising and having to conform to neurotypical standards of social interaction.

Our findings show that during the pandemic, children with SEND had their access and right to play, recreation, exercise and activities severely limited (Article 31, UNCRC). This is particularly problematic for children with sensory (vestibular) needs for movement, as evidence suggests a positive and consistent relationship between physical activity and children with SEND's wellbeing, mental health (Yang et al., 2021) and quality of life (Toscano et al., 2018). Before the pandemic, there were already many barriers to children with SEND participating in physical activity (Obrusnikova & Cavalier, 2011), with one being a lack of opportunities (Shields & Synnot, 2016). For example, children with SEND are often only permitted to attend summer holiday clubs part-time, and mainstream providers do not always have a good understanding of how to make clubs inclusive and accessible (Knight et al., 2009). Although SEND-specific clubs and activities exist, availability varies and they often have long waiting lists. By limiting access to the inclusive clubs already available, pandemic restrictions heightened barriers to physical activity. Moreover, given the importance of 'inclusive pathways with structured progression of participation' for children with SEND (as opposed to 'one-off' activity programs; Shields & Synnot, 2016, p. 6), the lack of continuity of physical activity clubs are likely to have negatively impacted children with SEND's ability to re-engage in physical activity following restrictions.

Our findings demonstrate a clear decline in mental health for many children with SEND, in line with existing evidence (e.g. Council for Disabled Children, 2021; Family Fund, 2021). While research with neurotypical children showed that, during the pandemic, many experienced sadness, anxiety and worries (e.g. Ashworth, Putwain, et al., 2022; Waite et al., 2022), the negative effects of pandemic restrictions are likely to have been greater in children with SEND. For example, while Castro-Kemp and Mahmud (2021) found that most children's mental health was positively impacted when schools re-opened, Skripkauskaitė et al. (2021) found that mental health difficulties for children with SEND did not improve in the same way. Given that children with SEND were already significantly more likely to be diagnosed with a mental health condition (NHS Digital, 2018) pre-pandemic, the restrictions appear to have further added to the health inequalities children with SEND face. Additionally, aligned with existing research (e.g. Toseeb & Asbury, 2022), autistic children's mental health was particularly negatively impacted by pandemic-related routine changes.

Parents in this study reported that the majority of children with SEND did not go to school full-time during the first lockdown, even if they had an EHC Plan that specified they should have been offered a place. This aligns with previous research by The Children's Commissioner for England (2020), who found that only 6% of children with EHC Plans went to school between March and May 2020. This is especially problematic for children with SEND who receive health and social care provision in school, as not attending meant that they also lost much of the wider support they received.

Furthermore, our findings support previous research suggesting that remote learning did not work well for most children with SEND (e.g. Canning & Robinson, 2021; Council for Disabled Children, 2021; Shaw & Shaw, 2021), as children struggled to comprehend why they were being asked to do schoolwork at home and the educational resources provided to help them learn from home were not accessible. This provides further evidence of a deficit in education provision for children with SEND, despite Article 28 of the United Nations (1989), the Equality Act (2010) and the CFA (2014), which denote that, by law, teachers must respond to the needs of *all* children in mainstream schools. Additionally, most parents reported their children were not given the technology required to engage in home learning. Therefore, remote learning is likely to have worked more effectively for more socially advantaged groups, who could afford to purchase resources (Shaw

& Shaw, 2021). Given that children with SEND are more likely to be exposed to poverty (Shaw et al., 2016; Skipp et al., 2021), it is probable that they have been disproportionately disadvantaged.

Regarding health care, our findings indicate that most children with SEND could not access appropriate provisions; this aligns with Article 24 of the United Nations (1989), where every child has the right to the best possible health. While access to healthcare services was a challenge for many during the pandemic, children with SEND's services ceased overnight (Alghrani & Byrne, 2020). Essential services outlined in EHC Plans such as 1-to-1 educational support, mental health support, speech and language therapy, occupational therapy, physiotherapy and hydrotherapy were discontinued. In the current study, parents noted that staff had been redeployed to COVID-19-related duties. In the UK, there were 122 508 deaths from COVID-19 (as an underlying cause) between 3 January 2020 and 2 April 2021 (ONS, 2021), of which 37 were children. As COVID-19 was far less likely to cause death in children than in adults, this suggests that the redeployment of healthcare professionals to COVID-19-related duties was done to protect adults, thus overlooking the rights and needs of children.

Finally, parents reported in this study that respite ceased, and there was very little support for the families. This aligns with previous research which illustrated that families of children with SEND have been left exhausted and in despair (Family Fund, 2021; OFSTED, 2021), with no break from caring responsibilities, and a sense of abandonment by health and social care services (Rogers et al., 2021). School is not just a place for education and learning for children with SEND, it also provides parents with respite from the full-time care of their child (Family Fund, 2021). As such, the impact of not attending school during pandemic restrictions also had a knock-on impact on the wellbeing of parents/carers.

Limitations

The current study had several limitations that need to be considered. Firstly, the parents who took part in the study were self-selected and, as such, may not be representative of the entire population of SEND parents/carers. Indeed, the parents/carers who struggled the most during lockdown may not have had time to take part. Furthermore, as the survey was online, some parents/carers may not have had access to the necessary technology; thus, it is possible that we may not have reached some of the families who were most isolated. In addition, online surveys/interviews do not meet the needs of all children with SEND. While we attempted to address this through the use of creative response formats in surveys, and flexibility in the interviews, it is entirely possible that not all children's needs were accounted. These limitations regarding accessibility may well have contributed to the small sample size of children with SEND. Finally, as the study was cross-sectional, cause and effect cannot be established.

Conclusion

This study found that English Government legislation around pandemic restrictions did not take children with SEND's needs and rights into consideration. In turn, this appears to have had a detrimental effect on children with SEND, heightening the stark inequalities children with SEND already faced prior to the pandemic. Children with SEND's rights should be prioritised in all Government decision-making, as well as policy and funding.

ACKNOWLEDGEMENTS

We would like to thank all the children and their parents/carers who have shared their views, experiences and time with us. We would also like to thank the parent advisors and young people we consulted to help design the study as well as the Steering Committee for their ongoing guidance and support.

FUNDING INFORMATION

This work was supported by the National Institute for Health Research (NIHR) Policy Research Programme fund (grant number NIHR202718). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

CONFLICT OF INTEREST STATEMENT

The authors report that there are no competing interests to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Emma Ashworth  <https://orcid.org/0000-0002-5279-4514>

Lucy Bray  <https://orcid.org/0000-0001-8414-3233>

Amel Alghrani  <https://orcid.org/0000-0003-0413-5263>

REFERENCES

- Alghrani, A., & Byrne, S. (2020). *The impact of COVID-19 on education and children's services*. UK Parliament. <https://committees.parliament.uk/writtenevidence/5816/pdf/>
- Ashworth, E., Hunt, A., Chopra, J., Eames, C., Putwain, D. W., Duffy, K., Kirkby, J., McLoughlin, S., & Saini, P. (2022). Adolescents' lockdown-induced coping experiences (ALICE) study: A qualitative exploration of early adolescents' experiences of lockdown and reintegration. *The Journal of Early Adolescence*, 42(4), 514–541.
- Ashworth, E., Putwain, D., McLoughlin, S., Saini, P., Chopra, J., Rosser, B., & Eames, C. (2022). Ordinary magic in extraordinary circumstances: Factors associated with positive mental health outcomes for early adolescents during the COVID-19 pandemic. *Adversity and Resilience Science*, 3(1), 65–79.
- Berndt, T. J. (2004). Children's friendships: Shifts over a half-century in perspectives on their development and their effects. *Merrill-Palmer Quarterly*, 50(3), 206–223.
- Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37–47.
- Bray, L., Blake, L., Protheroe, J., Nafria, B., de Avila, M., Ångström-Brännström, C., & Robichaud, F. (2021). Children's pictures of COVID-19 and measures to mitigate its spread: An international qualitative study. *Health Education Journal*, 80(7), 811–832.
- Byrne, S. (2020). *The impact of COVID-19 on children with special educational needs and disabilities*. University of Liverpool.
- Canning, N., & Robinson, B. (2021). Blurring boundaries: The invasion of home as a safe space for families and children with SEND during COVID-19 lockdown in England. *European Journal of Special Needs Education*, 36(1), 65–79.
- Castro-Kemp, S., & Mahmud, A. (2021). School closures and returning to school: Views of parents of children with disabilities in England during the Covid-19 pandemic. *Frontiers in Education*, 6, 666574.
- Children's Commissioner. (2020). *Childhood in the time of Covid*.
- Council for Disabled Children. (2021). *Lessons learnt from lockdown: The highs and lows of the pandemic's impact on disabled children and young people: Children and young people's summary*.

- Creswell, J., & Plano-Clark, V. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209–240). Sage.
- Disabled Children's Partnership. (2018). *Secret life of us campaign: The case for a Disabled Children's fund*.
- Family Fund. (2021). *The impact of Coronavirus: A year in the life of families raising disabled and seriously ill children and young people*. <https://publications.parliament.uk/pa/cm201919/cmselect/cmeduc/20/20.pdf>
- House of Commons Education Committee. (2019). *Special educational needs and disabilities: First report of session 2019*. <https://publications.parliament.uk/pa/cm201919/cmselect/cmeduc/20/20.pdf>
- Knight, A., Petrie, P., Zuurmond, M., & Potts, P. (2009). 'Mingling together': Promoting the social inclusion of disabled children and young people during the school holidays. *Child & Family Social Work*, 14(1), 15–24.
- Morse, A., Banfield, M., Batterham, P., Gulliver, A., McCallum, S., Cherbuin, N., Farrer, L. M., & Calear, A. (2022). What could we do differently next time? Australian parents' experiences of the short-term and long-term impacts of home schooling during the COVID-19 pandemic. *BMC Public Health*, 22(1), 1–9.
- NHS Digital. (2018). *Mental health of children and young people in England, 2017: Summary of key findings*. <https://files.digital.nhs.uk/A6/EA7D58/MHCYP%202017%20Summary.pdf>
- Obrusnikova, I., & Cavalier, A. (2011). Perceived barriers and facilitators of participation in after-school physical activity by children with autism spectrum disorders. *Journal of Developmental and Physical Disabilities*, 23(3), 195–211.
- OFSTED. (2021). *SEND: Old issues, new issues, next steps*. <https://www.gov.uk/government/publications/send-old-issues-new-issues-next-steps/send-old-issues-new-issues-next-steps?s=09>
- O'Hagan, B., & Kingdom, S. (2020). Experiences of children with special educational needs and disabilities and their families in the UK during the coronavirus pandemic. *Tizard Learning Disability Review*, 25(4), 229–235.
- ONS (Office for National Statistics). (2021). *UK deaths due to COVID-19*. <https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/ukdeathsduetocovid19>
- Rogers, G., Perez-Olivas, G., Stenfort Kroese, B., Patel, V., Murphy, G., Rose, J., Cooper, V., Langdon, P. E., Hiles, S., Clifford, C., & Willner, P. (2021). The experiences of mothers of children and young people with intellectual disabilities during the first COVID-19 lockdown period. *Journal of Applied Research in Intellectual Disabilities*, 34(6), 1421–1430.
- Shaw, B., Bernardes, E., Trethewey, A., & Menzies, L. (2016). *Special educational needs and their links to poverty*. Joseph Rowntree Foundation.
- Shaw, P., & Shaw, A. (2021). COVID-19 and remote learning: Experiences of parents supporting children with special needs and disability during the pandemic. *Education*, 3(13), 1–15.
- Shields, N., & Synnot, A. (2016). Perceived barriers and facilitators to participation in physical activity for children with disability: A qualitative study. *BMC pediatrics*, 16, 9.
- Skipp, A., Smith, S., & Wall, D. (2021). Learning from the COVID crisis for educating children and young people with SEN/disabilities. *Journal of Research in Special Educational Needs*, 21, 168–184.
- Skripkauskaitė, S., Shum, A., Pearcey, S., McCall, A., Waite, P., & Creswell, C. (2021). *Changes in children's mental health symptoms from March 2020 to June 2021 (Report 11): Co-SPACE study*. University of Oxford.
- Smith, B., McGannon, K., & Williams, T. (2015). Ethnographic creative nonfiction: Exploring the whats, whys and hows. In G. Molnar & L. Purdy (Eds.), *Ethnographies in Sport and Exercise Research* (pp. 73–88). Routledge.
- Toscano, C., Carvalho, H., & Ferreira, J. (2018). Exercise effects for children with autism spectrum disorder: Metabolic health, autistic traits, and quality of life. *Perceptual and Motor Skills*, 125(1), 126–146.
- Tooseb, U., & Asbury, K. (2022). A longitudinal study of the mental health of autistic children and adolescents and their parents during COVID-19: Part 1, quantitative findings. *Autism*, 27, 105–116.
- UK Legislation. (2010). *Equality Act 2010*. <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- UK Legislation. (2014). *Children and Families Act 2014*. <https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
- United Nations. (1989). *Convention on the rights of the child*. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
- Waite, P., Pearcey, S., Burgess, L., Sajid, E., Klampe, M., Sargent, M., & Lawrence, P. (2022). How the COVID-19 pandemic affected young people's mental health and wellbeing in the UK: A qualitative study. *PsyArXiv* [pre-print]. <https://doi.org/10.31234/osf.io/xmpw3>

Yang, W., Wong, S. H. S., Sum, R., & Sit, C. (2021). The association between physical activity and mental health in children with special educational needs: A systematic review. *Preventive Medicine Reports*, 23, 101419.

AUTHOR BIOGRAPHIES

Emma Ashworth is a Senior Lecturer in Psychology. Her research is in the field of child and adolescent mental health and educational psychology, with a particular focus on risk and resilience, mental health interventions and service provision for children with SEND.

Lucy Bray is a Professor of Child Health Literacy and a registered Children's Nurse. Her work explores how children and young people can be provided with health information in a meaningful and timely way. Lucy is also involved in programmatic work focused on children and young people living with long-term conditions and complex needs.

Amel Alghrani is a Professor of Law. Amel is recognised as a leading international expert in health law and ethics, with particular expertise in SEND law (e.g. school exclusions, Education Health Care Plans, right to special education, reasonable adjustments in schools).

Joanna Kirkby is a research assistant on the Ask Listen Act study. She has research experience in the impact of the COVID-19 pandemic on children and young people's mental health and in service provision for children with SEND.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Ashworth, E., Bray, L., Alghrani, A., & Kirkby, J. (2023). 'Vulnerable and abandoned'—The impact of the COVID-19 pandemic on education, health and social care provision for children with SEND: Children and parents' perspectives. *Children & Society*, 00, 1–18. <https://doi.org/10.1111/chso.12774>