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ORIGINAL ARTICLE

Parental concerns about the long-term impacts of Covid-19 pandemic restrictions on the health, education and development of their children with Down syndrome: A qualitative analysis

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Abstract

The Covid-19 pandemic significantly limited access to vital services and resources required to support the health, education and development of neurodivergent children, especially children with Down syndrome (DS). We undertook qualitative analysis of responses to open-ended questions exploring caregiver ($n = 194$) concerns about the impact of the pandemic restrictions on their children with DS. Results showed that parents were concerned about their child's mental and physical health during lockdowns, and reported that children found the social isolation and lack of routine particularly challenging. Restrictions also raised ongoing longer-term concerns. Parents reported that limited social contact affected the development of children's communication and social skills, and fewer group activities impacted weight and motor development. School closures affected academic progress and development of the skills required to navigate a classroom environment. Restricted access to healthcare services delayed diagnosis and treatment, and cancelled therapies disrupted speech and motor development; ongoing disruptions continued to limit opportunities to mitigate concerns. The interlinking impacts of multiple restrictions compounded the challenges, highlighting the importance of accessible social resources and system-wide support for the health and development of neurodivergent children. We urge practitioners, researchers and policymakers to collaborate with families to mitigate the long-term implications of the pandemic for children with DS.

KEYWORDS
children, Covid-19, Down syndrome, education, health, neurodivergent

Key points

- The Covid-19 pandemic disrupted the education, health services and therapies that support the development of neurodivergent children. Children with Down syndrome (DS) have an increased risk of health conditions and physical and cognitive delays that often require extensive support, yet DS-specific pandemic research is limited.
- Parents reported that lockdowns had a detrimental impact on children's mental health, behaviour and education. Managing children's needs was challenging without access to health and developmental support services.
- Restrictions affected children's communication and social skills, and delayed academic progress and their acquisition of the skills needed to navigate a classroom

environment. Limited access to activities and support services affected physical health, speech and motor development. These impacts disrupted their social life and ability to stay in mainstream education, widening the developmental gap.
- The interlinking impacts of multiple restrictions compounded the challenges, and ongoing disruption continued to limit opportunities to mitigate them. Findings highlight the importance of accessible social resources and system-wide support; we recommend collaborative, targeted interventions and support to mitigate the long-term impacts of the pandemic on children with DS.

INTRODUCTION

Neurodivergent children with chromosomal variations, such as those with Down syndrome (DS), represent a vital part of the neuro-biodiversity sphere (Chapman, 2020). The unique genetic differences mean children with DS experience the world through cognitive and developmental pathways that diverge from neurotypical and other neurodivergent children. As well as being at a higher risk of physical health conditions such as heart defects, hearing and/or vision loss, and gastrointestinal and immune conditions (Capone et al., 2018; Centers for Disease Control and Prevention, 2024), they often present with delays in speech, cognitive, motor and emotional development (Capone et al., 2018; Grieco et al., 2015). Given the breadth of the potential co-occurring conditions associated with DS, access to continuous medical oversight, tailored therapies and additional school support is imperative (Bull et al., 2011).

Since 2020, the research evidence has been clear: the Covid-19 pandemic had a great impact across different communities and services. In the UK, there were three national lockdowns which were accompanied by a number of different policies to contain outbreaks and minimise strain on healthcare services (UK Government, 2022b). Social distancing mandates disrupted access to vital support services, leaving families to manage their children's health, education and well-being with limited support (Asbury et al., 2021; Greenway & Eaton-Thomas, 2020; Jeste et al., 2020; Nixon et al., 2022; Toseeb et al., 2020).

Immediate concerns were raised about how these environmental disruptions were affecting children's mental health and well-being (Adıbelli & Sümen, 2020; Egan et al., 2021; Egan & Pope, 2022; Ford et al., 2021; Iacobucci, 2022; Irwin et al., 2022; Lodha & Kabra, 2021). Recent evidence suggests that neurodivergent children were disproportionately affected by the Covid-19 pandemic (Castle et al., 2024; Sicouri et al., 2023), though the impact of the pandemic was experienced differently across different neurodivergent groups (Castle et al., 2024; Martínez-Castilla et al., 2023; Mullen et al., 2024; Pagnamenta et al., 2023; Panchal et al., 2023; Pavlopoulou et al., 2020; UNESCO, 2020). The literature suggests that during the restrictions, there were three domains in which neurodivergent children were particularly affected: education, health and mental health. With regard to the latter, researchers reported that neurodivergent children presented with a significant increase in mental health problems and challenging behaviours (Asbury et al., 2021; Barišić et al., 2024; Castle et al., 2024; Sideropoulos, Sokhn, et al., 2023; Theis et al., 2021). In terms of their health, they struggled to access necessary healthcare and developmental support, as well as experiencing an increase in physical health problems due to reduced physical activity levels, poorer diet and worse sleep hygiene (Adıbelli & Sümen, 2020; Amatori et al., 2022; Masi et al., 2021; Theis et al., 2021). Finally, all children, including neurodivergent children, were left behind in education (UK Parliament, 2021; UNESCO, 2020). However, restrictions had a greater negative impact on the academic performance of neurodivergent children during the pandemic than on their typically developing peers (Panagouli et al., 2021; Paterson et al., 2023). In addition, they found disruption to schooling more challenging than their neurotypical counterparts due to prolonged periods without access to structured routines and vital educational support. For instance, only between 4% and 10% of vulnerable children attended school during the first lockdown. This only increased to 17% when schools fully reopened in June 2020 (UK Government, 2022a), with parents citing concerns about the risk of infection and lack of classroom resources (UK Government, 2021). Although online alternatives to schooling were often provided, neurodivergent children often faced challenges in engaging remotely, and resources were often not tailored to their needs (Greenway & Eaton-Thomas, 2020; Nixon et al., 2022; Thorell et al., 2022; Van Herwegen et al., 2020).

Children with DS were particularly vulnerable to these impacts due to their increased need for integrated health, educational and developmental support (Bull et al., 2011). Existing literature highlights similar challenges with remote education and physical activity, and as many as 90% of children with DS experienced delays or cancellations to routine healthcare appointments (Nixon et al., 2022). Mental health impacts were also evident, with children with DS presenting with increased anxiety and behavioural challenges (Barišić et al., 2024; Castle et al., 2024; Pagnamenta et al., 2023; Sideropoulos, Kye, et al., 2023; Sideropoulos, Sokhn, et al., 2023). The restricted social contact particularly impacted the well-being of children with DS; they found the social aspects

of lockdown more worrying than other children, and concerns were raised about how social isolation was affecting children's communication, learning and development (Pagnamenta et al., 2023; Sideropoulos, Kye, et al., 2023).

As the immediate repercussions of the pandemic subside, it is important to address the longer-term impact that the disruptions had on neurodivergent children (Care Quality Commission, 2024; Egan et al., 2021; Egan & Pope, 2022; Mullen et al., 2024; Torjesen, 2024), including those with DS. Taking a holistic view when considering how to provide the necessary support is key; Egan and Pope (2022) recommend that the impacts of disruptions to the wider education and care system need to be jointly considered in order to fully understand and mitigate the impact of the pandemic on children (Egan & Pope, 2022). However, despite calls for tailored and holistic approaches to research, there is limited research focusing on the pandemic's long-term impact on the education, health and development of children with DS beyond reporting the challenges (Mullen et al., 2024; Paterson et al., 2023).

Our article aims to address this gap by considering how the pandemic restrictions continued to affect children with DS beyond their enforcement, reflecting on the compounding impact that disruptions to their environment may have had on their education, health and development. As considering the views of families of neurodivergent children is a crucial part of developing effective interventions to address these challenges (DfE, 2022; Fortea et al., 2024; Hendrix et al., 2020; Satherley et al., 2021), we investigate through qualitative analysis of parental concerns about long-term impacts of the pandemic restrictions on children with DS, reflect on the implications, and provide recommendations for policy and practice.

METHOD

This study focuses on the answers of 194 participants ($n=443$) to open-text questions ($n=5$) from an online survey investigating the impact of the pandemic on children aged under 11 years with DS in the UK. The survey was divided into six categories: demographics, education, healthcare, physical health, mental health and behaviour. A variety of question types were employed, including five-point Likert scales, multiple-choice questions and free-text responses. The survey link was distributed online using a 'digital snowballing' technique, which involved sharing links on social media and collaborating with charities and support groups across the country. Participation was voluntary and conducted anonymously online, and all questions were optional. Study data were collected and managed using REDCap electronic data capture tools hosted on a secure server at University College London in line with the Data Protection Act 2018 (Harris et al., 2009). The survey was open for three months from November 2021 to February 2022 and received ethical approval from UCL Research Ethics Committee (10901/002).

Community participation

The research team worked with the Down Syndrome Association and, Trisomy 21 Research Society and parents of children with DS to better respond to the lived experiences shared by families. Drawing on participatory research principles outlined by Fletcher-Watson et al. (2021), parents, charities and experts were consulted throughout the study to ensure that the wording was sensitive to the demographic and that the questions were easily understood and relevant (Fletcher-Watson et al., 2021).

Participants

The eligibility criteria for the survey were as follows: (i) to be a parent/caregiver for a child aged 11 or under with DS; (ii) to have access to the internet; (iii) to be able to understand English; and (iv) to have lived in the UK during the pandemic. To be included in the sample for this analysis, participants had to have answered at least one of the written questions pertaining to the impact of the pandemic on their children. We received a total of 241 responses, of which 194 were eligible for this qualitative analysis. Children in our sample were primarily female ($n=98$; 50.5%), White ($n=173$; 89.2%) and living in England ($n=156$; 80.4%). Four of our respondents were grandparents; however, this article will refer to them under the banner of 'parents' or 'caregivers'. A demographic breakdown of respondents is presented in Table 1.

Analysis

Responses ($n=443$) to five open-ended questions were analysed using thematic analysis, a reflexive method that can be used to identify patterns within data without a pre-existing theoretical framework (Braun & Clarke, 2019). Taking a blended inductive/deductive approach allowed us first to refine the research question and ensure relevant data were included. The first and second authors approached answers to a question about participants' top three concerns about the impact of the pandemic on their children inductively ($n=194$), independently reviewing and describing the data for general parental concerns (e.g. health). Joint comparison and discussion of these findings with the fourth author identified high-level themes (i.e. education, social, communication and health), leading to the decision to add

TABLE 1 Participant demographics.

Category	Frequency	%	% (cumulative)
Gender			
Male	96	49.5	49.5
Female	98	50.5	100.0
Ethnicity			
Asian/Asian British	2	1.0	1
Black/Black British	1	0.5	1.5
Mixed/multiple ethnic groups	17	8.8	10.3
White	173	89.2	99.5
Prefer not to say	1	0.5	100.0
Country of residence			
England	156	80.4	80.4
Wales	5	2.6	83.0
Scotland	29	14.9	97.9
Northern Ireland	4	2.1	100.0
Household composition			
Both parents, same household	163	84.0	84.0
Both parents, separate households	3	1.5	85.5
Single parent	16	8.3	93.8
Extended family	12	6.2	100.0

responses to four more open-ended questions on these topics to gain a richer understanding of these concerns. After reviewing the expanded dataset with these themes in mind, the authors identified that participants often described their concerns and impacts as consequences of certain restrictions; this informed the development of a coding framework focused on the specific restrictions that the pandemic incurred (i.e. social restrictions, limited access to healthcare, and school closures).

The first and second authors subsequently double-coded the data deductively for emerging themes (e.g. social anxiety, academic attainment) and iteratively met to discuss and refine them with the fourth author, remaining conscious that interpretations may be influenced by their professional and personal positionality (Coghlan & Brydon-Miller, 2014). The use of iterative investigator triangulation aimed to increase both the validity and inter-rater reliability of resulting themes (Noble & Heale, 2019) and allowed for a more thorough exploration of the data (Denzin & Lincoln, 2008). All data were coded manually by the first and second authors in Microsoft Excel.

RESULTS

Parents were greatly concerned about how social restrictions, school closures and limited access to support services had affected their children with DS across their education, health and development. Families described the immediate disruptions they experienced and reflected on their ongoing concerns about the long-term consequences (see Figure 1 and Table 2).

Social restrictions

Social restrictions limited interactions with existing family and friends, opportunities to learn how to make new connections and exposure to larger groups of people. As families were highly concerned about the potential impact of the Covid-19 virus on their child, many adhered to social restrictions longer than was mandated.

Children struggled with the lack of social connection and frequently expressed how much they missed interacting and playing with peers and family: *'he was longing for contact … and kept asking to see family and friends over and over'* (P178). Parents described their children as depressed, anxious and lonely as a result of this isolation, and that they struggled to help them understand what was happening.

In addition, social restrictions disrupted access to group activities, leading to fewer opportunities for exercise, developing new skills and *'opportunities to be verbal & communicate … outside of the household*' (P60).

Parents were concerned about the ongoing impacts that these restrictions had had on their children's social and physical development.

Social skills and behaviour

Many respondents noticed a concerning deterioration in their child's social skills once restrictions had lifted. Parents shared that their children had suddenly *'struggled to interact'* (P143), and were worried that their children could no longer *'socialise appropriately'* (P53).

Some children had become more aggressive towards their peers, with one parent reporting that being out of the habit of interacting with others meant that her son began *'pushing and shoving other children once [they] were able to get closer to others again'* (P56). These behaviours were not improving, and parents were *'worried that [their] child's social skills [would not] return properly'* (P100).

Communication

Many parents had noted a deterioration or delay in speech and communication skills: '*being non verbal has lasted a lot longer than it should because of lack of social interaction with other children his age'* (P134). This created challenges when returning to social environments, as *'other people outside the household couldn't understand'*

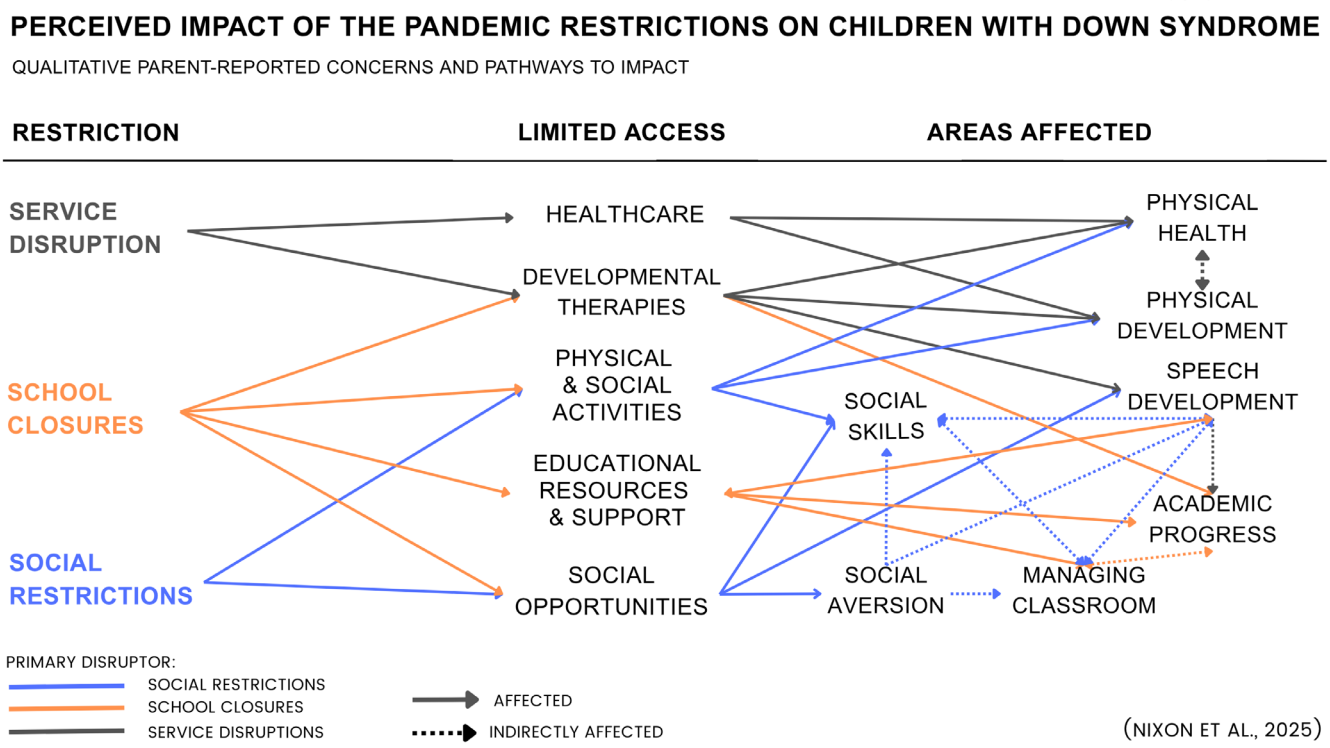

FIGURE 1 Perceived impact of the pandemic restrictions on children with Down syndrome: Qualitative parent-reported concerns and pathways to impact.

what they were saying (P14). Parents were concerned about how this would impact their children's social life; one child had *'no school friends as they [did] not understand her'* (P150), while another parent reported that children *'joke at [their son's] expense'* as he is *'perceived by peers to be inarticulate'* (P216).

Conversely, some parents found that more individual time with their child benefited their children's speech and communication skills, though some recognised that for younger children some progress would be expected naturally: *'[his communication has] improved as has had lots of time with familiar people he is comfortable with, but would expect a big improvement at this age anyway'* (P131).

Parents noted that a lack of developmental support had compounded the impact of social restrictions on communication (see 'Results' section 3.1).

Social aversion

The majority of parents described their children as more reserved than before the pandemic, and that restrictions had made them more wary of engaging with others:

> [my daughter] was very sociable and loved running up to people to greet them but because this was not allowed during the pandemic, she [has] become much more reserved and hesitant.
>
> (P113)

This had made some children uncomfortable in public spaces, with parents reporting that their children became anxious *'if [they went] anywhere with lots of people'* (P4) or *'overwhelmed in busy/crowded situations'* (P58), some even crying or having *'meltdowns whenever [they] accessed any open outdoor areas'* (P228).

This fear extended to private interactions, with some children not being comfortable engaging one-on-one and struggling with people they did not know entering their home: *'Her fear of other people (not immediate family/local grandparents) coming into her house [is my main concern]. She was terrified and angry when this happened recently'* (P53).

Some children became dependent on their caregivers due to spending so much time with them during lockdown. Parents were concerned that those who were previously independent were thought to be *'more reliant on [their parents] for comfort'* (P170) and *'more attached, … more clingy and less independent'* (P227).

Parents were worried about the effect of these anxieties on their children's ability to return to school and their regular routine (see 'Results' section 2.2).

Physical health and development

The limited opportunities for physical activities had affected children's weight: *'Not being able to go out, do his extra activities playing at parks, going swimming, interacting with family and friends caused significant weight gain'* (P218). Parents worried about the health consequences

TABLE 2 Sample of survey answers by code and theme.

Restriction	Concern	Sample of survey answers
Social restrictions	Social skills and behaviour	'My daughter has always been very polite and understanding of what behaviour is required in social situations. After lockdown she will say it's time to go bye when we just get somewhere after that she will switch off' (P68). 'I'm worried her social skills won't return properly' (P100). 'She doesn't know how to interact appropriately with peers as she hasn't had the correct opportunities' (P181). 'My son now struggles to socialise appropriately' (P58). 'He was out of the habit of face-to-face interaction, and his behaviour got more challenging in terms of pushing and shoving other children once we were able to get closer to others again' (P56). 'She's started to be very direct when she doesn't want to visit people now she says very loudly, Let's go home' (P238). 'Being socially isolated during the pandemic has made my son to fixate on wanting to ring, visit, people, no matter wether [sic] its the Doctors, supermarket, leisure centre, etc.' (P148).
	Communication	'Lack of communication and interaction with others definitely caused him to regress alot in terms of saying single words' (P218). 'Lack of interaction with peers—has affected language and social skills' (P233). 'being non verbal has lasted a lot longer than it should because of lack of social interaction with other children his age' (P134). 'his talking has been perceived by peers to be inarticulate so he isn't able to access it successfully. Sometimes children would joke at his expense on Zoom when he tried to engage' (P216). 'Her communication and social interaction has deteriorated as has her desire to communicate with others' (P80). 'She developed a stammer put down to stress of lockdown' (P232). 'I could tell what my son was saying but other people outside the household couldn't understand' (P14).
	Social aversion	'My son seemed withdrawn, quiet, less confident, isolated, shy, uncommunicative & sometimes agitated' (P43). 'Pre-pandemic [my daughter] was very sociable and loved running up to people to greet them but because this was not allowed during the pandemic, she [had] become much more reserved and hesitant' (P113). 'My daughter used to be very affectionate and would hug friends and family … She is wary now' (P95). 'Her fear of other people (not immediate family/local grandparents) coming into her house [is my main concern]. She was terrified and angry when this happened recently' (P53). 'He becomes overwhelmed in busy/crowded situations. I feel that this is a regression' (P58). 'Being forced to stay away from people had a negative impact, we had meltdowns if we visited any open outdoor areas' (P229). 'Anxiety now if we go anywhere with lots of people' (P4). 'He is much more clingy and less independent' (P227). 'Fearful and anxious of people when lockdown lifted crying and clingy to carers' (P37). 'They became more reliant on us for comfort. Experienced a lot of separation anxiety when lockdowns lifted and relatives able to visit again' (P107). 'They became more sensitive to noise and to groups of people as they'd become used to just being at home with me as sole parent. They were much more reticent with new people than before lockdown' (P63). 'Our daughter's lack of experience of new people/places and the fact she now gets anxious in these circumstances' (P197).
	Physical health and development	'Not being able to go out, do his extra activities playing at parks, going swimming, interacting with family and friends caused significant weight gain. He has low muscle tone and struggles to keep up with his peers so has always been on the heavier side but always tried to keep up with his friends' (P218). 'Much less physical exercise during lockdowns which meant delays in [my daughter] building her strength (e.g., she still can't walk down stairs)' (P136). 'Her physical health has deteriorated and we are waiting for further investigation' (P80). 'She has put on weight and now is actually unable to do any activities because she actually hasn't got the strength no stamina to do it' (P68).

TABLE 2 (Continued)

Restriction	Concern	Sample of survey answers
School closures	Academic progress	'She is not able to achieve the targets she had set 3 academic years ago which she was able to do' (P80). 'Missed out on over a year of formal education—already behind peers and so much wasted time has widened the gap' (P233). 'Change from mainstream school to SEND earlier than planned as lack of learning opportunities during lockdown' (P11). 'Further educational delays eg speech and reading and maths' (P38). 'She's not had the same level of support for her needs, while in school. It was more play focused and not so much about the curriculum it being taught from her EHCP [sic]. So she's more behind than she should be' (P29).
	Ability to manage a classroom environment	'My daughter, who was already very sound-sensitive, became even more so during lockdown, as she got used to everything being quieter. She now can't bear to be around any other children and struggles with adults with louder voices. She has had to leave mainstream education as a result' (P223). 'They thrived when back at school under key worker and SEN scheme with a smaller class. But main concern was going back to full time and full class and back to going out and dealing with stress caused by extra sensory input that was not there during the pandemic. And any progress made in coping with these issues was lost' (P143). 'Has no school friends as they do not understand her' (P150). 'Difficult settling back into school life and routines on return' (P127).
Disruption to health and support services	Speech and language development	'Decline in spoken language and eye contact, more repetitive language and less expressive language' (P129). 'A lack of access to therapy has meant his progress has been very slow, with better support we could have helped him more' (P184). 'Sounds that he used to make and words he used to say have deteriorated, he's definitely regressed' (P118). 'He didn't get any of the weekly early interventions that he would have had. I think he would have been a lot more able to socialise better, turn take and be more focussed if he had had this' (P209). 'Significant break in early years support in-person (e.g., SLT, OT). Meant we were less supported as parents and [my daughter] not getting the input she needed' (P129). 'She is not been [sic] supported by SLT services or hearing teacher despite regular requests she has fallen even more behind' (P150).
	Physical health and development	'Appointments missed which could have assisted in her speech, social skills and mobility, this could have caused her to be more delayed than she needed to be' (P119). '[Her] development really stagnated. Her walking and talking is very delayed I think due to very little support for nearly 18 months' (P169). 'No school, no physiotherapy, no speech therapy and no occupational therapy had large impact on his muscle tone and communication' (P41). 'Her physical health has deteriorated and we are waiting for further investigation' (P80). 'She also hasn't had the developmental support from speech & language, physio ect [sic] to bring on her communication and mobility' (P214).
	Opportunities to mitigate challenges	'I am concerned that [their] physical and developmental health will continue to deteriorate unless appropriate thought is put into how to engage and support children to access healthcare and other resources' (P80). 'Strain on NHS and people leaving the NHS leading to lack of people with real expertise on Down Syndrome' (P168). 'Changed patterns of support at school ie lack of support has become the norm and expectations have lowered for his learning' (P216). 'He lacked support before the pandemic and have to fight for every appointment. Now, that's tripled and I'm fighting harder than ever for him to be seen' (P227). 'I wonder if money is till [sic] readily available to support her now and in the future' (P24).

and how this would limit children's ability to engage in social and physical activities now that activities had resumed: *'she [is] unable to do any activities because she actually hasn't got the strength no[r] stamina to do it*' (P68).

Additionally, reduced physical activity was impacting children's ability to hit key physical developmental milestones: *'Much less physical exercise during lockdowns which meant delays in [my daughter] building her strength (e.g., she still can't walk down stairs)'* (P136). Parents were limited in mitigating these concerns by the lack of access to developmental support (see 'Results' section 3.2).

School closures

School closures had contributed to a *'deterioration in behaviour due to lack of structure and routines'* (P95). Children struggled to engage with remote learning and often were not afforded their usual level of support, leaving parents to manage their education with limited access to appropriate materials. Despite some parents reporting benefits to one-on-one time, the majority found supporting their child challenging: *'it took all of my efforts to structure her day and teach her full time'* (P29). Additionally, school closures had exacerbated the impacts of other restrictions, with many reporting reliance on schools to access their children's social resources, therapies and extra-curricular activities.

Time away from in-person education was thought to affect children's academic progress and their ability to navigate a classroom environment on their return to school.

Academic progress

Parents felt that academic progress was significantly affected by the gap in education: *'My child has regressed in academia. She is not able to achieve the targets she had set 3 academic years ago'* (P80). This was having large impacts on the future of their education, as many children were *'already behind peers'* and school closures had *'widened the gap'* (P233); several children had already had to *'change from mainstream school to SEND earlier than planned as lack of learning opportunities during lockdown'* (P11) and another was having to retake the school year. Parents worried that they would not catch up and that this would have consequences on their future development.

Ability to navigate a classroom environment

School closures meant children were not used to a classroom environment, and several children struggled to readjust to the *'extra sensory input that was not there during the pandemic'* (P143). One parent described how her daughter struggled to the extent that she had to leave mainstream education: *'she now can't bear to be around any other children and struggles with adults with louder voices'* (P223). A few parents had found one-to-one home learning beneficial for their child's development; however, this had led to concerns on their return to school as some of these children were not thriving as much due to the comparative lack of individual support: '*Now [my son] is back at School his speech has deteriorated. There is no 1 to 1 SALT [speech and language therapy] support'* (P229).

The detrimental impact of the social restrictions (see 'Results' section 1) was thought to contribute to these challenges, as many children had not developed the level of social skills and confidence required to navigate group environments.

Disruption to health and support services

Parents found it challenging to access necessary support services, and many were *'not able to access the right healthcare to support [their child's] needs'* (P56). Children were awaiting diagnostic assessments, missing regular therapy appointments, and facing disruptions to routine and specialist healthcare; several had not seen a paediatrician in person in years.

Parents shared that they lacked the time, knowledge or resources to provide the support their children needed by themselves, especially those who worked: *'we were less supported as parents and [my daughter was] not getting the input she needed'* (P129). This took a toll on parental mental health, which they felt had further impacted their children: *'my stress levels definitely affected her'* (P63).

Parents were concerned that this lack of support would have long-term impacts on their children's health, education and development, and were worried service delays would limit opportunities to mitigate these challenges.

Speech and language development

One of the most prevalent concerns for parents was a lack of SALT provision, with service disruptions exacerbating the impact the restrictions had had on children's speech and communication skills (see 'Results' section 1.2): *'SALT stopped completely which has impacted language development'* (P172). Many had seen a *'decline in spoken language and eye contact, more repetitive language and less expressive language'* (P129) and a child who was *'normally quite fluent … started stumbling over her words'* (P10). Parents were worried about the consequences of children's speech and communication skills having *'fallen even more behind'* (P150) for their education and social skills—exacerbating the existing impacts of the pandemic:

> he didn't get any of the weekly early interventions that he would have had. I think he would have been a lot more able to socialise better, turn take and be more focussed if he had had this.
>
> (P209)

Physical health and development

A lack of access to regular physiotherapy appointments limited the development of motor skills and muscle strength: *'no physiotherapy … and no occupational therapy*

had [a] large impact on his muscle tone' (P41). These impacts were exacerbated by the lack of support available to manage the negative impact of reduced physical activity on children's weight and development: *'I've requested help to [the] paediatrician for a dietician but nobody cares'* (P68). This created concerns about children's future ability to take part in social activities and exercise (see 'Results' section 1.4).

Parents were worried about how the gap in services would affect children's general health, with many still awaiting diagnostic assessments or care: *'Her physical health has deteriorated and we are waiting for further investigation'* (P80).

Opportunities to mitigate damage

Parents were concerned that the pandemic's disruption to services would exacerbate challenges they had already been facing pre-pandemic: *'he lacked support before the pandemic and have to fight for every appointment. Now, that's tripled and I'm fighting harder than ever for him to be seen'* (P227).

Parents had noticed a decrease in SEND support in classrooms since returning to school, reporting that their children had *'not had the same level of support for [their] needs'* (P29) and that a *'lack of support has become the norm'* (P216). They were concerned this would limit opportunities to counter the educational disruptions, further widening the attainment gap for neurodivergent children.

Parents were worried about how the direct impacts of the pandemic would be mitigated without this access, and that the ongoing disruption would continue to affect their children without a concerted effort by service providers:

> I am concerned that [their] physical and developmental health will continue to deteriorate unless appropriate thought is put into how to engage and support children to access healthcare and other resources.
>
> (P80)

DISCUSSION

School closures, reduced access to support services, and social restrictions led to immediate and long-term concerns for families of neurodivergent children (Castle et al., 2024; Masi et al., 2021; Nixon et al., 2022; Sideropoulos, Kye, et al., 2023). To our knowledge, this is the first study to focus on understanding in detail the parental concerns of children with DS during the Covid-19 pandemic. In this section, we discuss our key findings and their implications, and provide recommendations for practitioners.

Our qualitative findings highlighted that the parents' immediate concerns were primarily focused on the impact of limited opportunities on their child's mental health and their own ability to support children without access to professional assistance. Their experiences align with the findings of Sicouri et al. (2023), whose survey of 1327 parents and carers found that neurodivergent children presented with worse mental health symptoms during the initial stages of the pandemic than neurotypical children (Sicouri et al., 2023). Likewise, Chafouleas and Iovino (2021) reported higher psychological distress among parents of neurodivergent children compared to those with neurotypical children, highlighting the disproportionate challenges faced by these families during the pandemic (Chafouleas & Iovino, 2021; Willner et al., 2020).

As restrictions eased, concerns shifted towards the enduring developmental, educational and health challenges caused by limited access to resources (Figure 1). Parents reported delays or regression of speech, social and motor development that were continuing to affect their children's ability to participate in school and recreational activities. Limited access to appropriate educational resources further exacerbated existing worries about children's academic futures and their readiness for mainstream schooling. Disruptions in health and support services compounded these effects, and parents of children with DS feared the ongoing delays would reduce opportunities to mitigate health and developmental challenges moving forward. Crucially, these impacts often did not act in isolation but interacted synergistically—social restrictions, reduced therapies and limited medical support collectively hindered speech development, which in turn constrained the social skill acquisition necessary for classroom adaptation, ultimately raising academic concerns (Figure 1). This highlights the need for a holistic view of the ecosystem surrounding children with DS, rather than addressing developmental domains separately (Egan & Pope, 2022).

Our findings resonate with broader neurodivergence research on the pandemic's impacts, which commonly reports immediate consequences such as disrupted routines, mental health deterioration, educational challenges and reduced physical activity (Adıbelli & Sümen, 2020; Amatori et al., 2022; Masi et al., 2021; Nixon et al., 2022; Theis et al., 2021). However, longitudinal data remain scarce (Mullen et al., 2024), despite professional and familial concerns about lasting academic, developmental and caregiver well-being issues (Egan et al., 2021; Egan & Pope, 2022; Greenway & Eaton-Thomas, 2020; Irwin et al., 2022; Masi et al., 2021; Pagnamenta et al., 2023; Willner et al., 2020). Notably, although communication and health were mentioned in general literature on neurodivergence, they emerged as more central concerns in our DS-focused study (Barišić et al., 2024; Castle et al., 2024; Pagnamenta et al., 2023). This difference may reflect the predominance of autistic participants

in neurodivergence research, where some studies found that reduced social interaction during the pandemic actually benefited mental health and behaviour (Morris et al., 2023; Spain et al., 2021). Moreover, a clinical study on children with language developmental disabilities reported no language decline post-pandemic, but this did not include children with DS (Ayuso-Lanchares et al., n.d.).

The heterogeneity within neurodivergence highlights the importance of tailoring research, interventions and resources to the unique challenges faced by children with DS; Castle et al. (2024) argues against a single, blanket response for neurodivergent children, as nuanced understanding of intersecting difficulties is essential for developing effective supports that address both immediate and long-term impacts (Castle et al., 2024).

Implications

Even short-term developmental delays in early life can have long-term implications for health, education and development, and the cumulative impacts of disruptions across these three domains may exacerbate the effects (Egan et al., 2021; Egan & Pope, 2022; Marmot & Bell, 2019). Our findings highlight the complex relationship between these areas from a parental perspective—but what are the potential wider implications of these challenges moving forward?

Children with DS are already at higher risk of obesity than the general population and the pandemic seemed to exacerbate this challenge, increasing the risk of developing health conditions to which they are already predisposed (e.g. cardiovascular and pulmonary conditions) (Bertapelli et al., 2016; Capone et al., 2018; Fryar et al., 2020; Loprinzi et al., 2015). Pandemic disruptions have meant that they still have limited access to diagnosis or management for these conditions, with the median NHS waiting time for referrals being 1.8 times higher in April 2025 than pre-pandemic in February 2020 (BMA, 2025). This delayed access to healthcare could compound the already negative effect of the pandemic on children's health, potentially creating further health challenges in the future (Lodha & Kabra, 2021; Torjesen, 2024). Similarly, children with DS are facing an average 2.5-year wait to access community health services and therapies (Children's Commissioner, 2024), limiting opportunities to mitigate developmental challenges. Parents were particularly concerned about speech and language development; without intervention, this could have life-long implications for social, educational and developmental functioning (Horwitz et al., 2003; Kasari & Freeman, 2001; Næss et al., 2017; Roberts et al., 2007).

Neurodivergent children are already facing a widening educational attainment gap, a disadvantage that puts them at greater risk of worse mental and physical health outcomes across the life course (Kosik et al., 2018; Marmot & Bell, 2019; Panagouli et al., 2021; Paterson et al., 2023). There were already concerns about the sufficient provision of the SEND support they require to mitigate this challenge pre-pandemic, yet schools are now even more limited in their resources; an increase in the number of Education, Health and Care Plans in place in England has left many local councils in deficit as they try to keep up with increasing demand (Benhenda, 2022; DfE, 2023; Butler et al., 2025). A lack of tailored support risks more children with DS being forced out of mainstream education, depriving them of the social and behavioural advantages of learning alongside neurotypical peers (Buckley et al., 2006; Hargreaves et al., 2021) and reinforcing the negative cycle that the pandemic started.

Recommendations

The impact of the Covid-19 pandemic has been complex and multifaceted, and system-wide, integrated support is necessary to mitigate the disruption. Decision makers, researchers and practitioners each have a role to play in addressing the long-term impacts of the pandemic on children with DS. Practitioners and educators should be wary of assuming the limits of a child's abilities based on their current level of development and recognise the value of investing in speech and social skills; providing educators with resources tailored to children with DS could help them to assess children's needs and provide appropriate support. The implications of moving children with DS away from mainstream education should also be carefully considered before making this decision; where it is unavoidable, it is key that appropriate guidance and support is provided to parents so they can navigate the challenges themselves. Decision makers have a responsibility to ensure that necessary resources are available for schools to continue providing this essential integrated support and facilitate access to vital health, educational and developmental services. Finally, we encourage researchers and funders to keep pandemic research on the agenda, and work alongside practitioners, decision makers and families to build tailored, evidence-based resources and solutions to mitigate the pandemic's impact on neurodivergent children.

Strengths and limitations

Though our data are situated in the context of the Covid-19 pandemic, the findings can be applied to any context where neurodivergent children have restricted access to community and social resources. Our large number of participants ($n = 194$)—far larger than is often found in qualitative samples—allowed us to capture a

wide range of experiences and provide more generalisable recommendations. However, our analysis was not able to go into the depth that would be found in interview data, and focusing on parental concerns meant our analysis was inherently deficit-based and we did not capture the lived experiences of the children themselves. Collaboration with parents and charities in the study's design and recruitment allowed us to tailor our study to their differing health and support needs, improving the relevance of our contribution to the limited DS-specific knowledge base.

CONCLUSION

The disruptions to the wider support systems for neurodivergent children during the Covid-19 pandemic have created notable concerns about the education, health and development of children with DS. Limited access to support and social resources across these domains concurrently has compounded their impact—with potentially life-long implications for health and well-being. As ongoing disruptions continue to limit opportunities to mitigate these challenges, developing targeted and effective solutions is crucial. We recommend that educators, healthcare professionals and policymakers work together alongside families to find ways to provide the additional integrated, tailored support needed to ensure the optimal health and development of children with DS.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author, Monica Lakhanpaul.

ETHICS STATEMENT

This study had ethical approval from UCL Research Ethics Committee (10901/002).

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