

Children with Down Syndrome in Lockdown

Key findings from a survey of parents of children under 11 with Down Syndrome in the UK

UCL t2i RESEARCH SOCIETY DOWN'S SYNDROME ASSOCIATION

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Foreword



The COVID-19 pandemic had a significant impact on children's lives, and we continue to see the knock-on effects the disruption has had on health and wellbeing.

The UK's COVID-19 Inquiry reports highlight that the impacts of pandemic restrictions on children's wellbeing and development were not sufficiently considered, and that this particularly affected those that benefit from additional support. As both a paediatrician and academic, I have seen first-hand the unique challenges that children with Down Syndrome and their families continue to face.

This report adds to this evidence base by summarising the findings of a survey on the impact of the pandemic on children with Down Syndrome under 11 in the UK. The survey ran from November 2021-February 2022. It is important to listen to families, and we aimed to shed some light on the experiences families had and highlight their concerns about the impact on their children's future across their health, education and development.

I hope this report will provide the groundwork for future research and inform strategies to support children with DS moving forward.



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Executive Summary

Down syndrome (DS) is a form of neurodivergence and chromosomal condition that can create varying levels of intellectual ability as well as a range of health complications, including heart defects, immune disorders, hearing and vision loss, and gastrointestinal conditions[1]. Children with DS benefit from access to a range of support services to help them achieve optimal health and development.

There were two major lockdowns in the UK as well as additional region-specific restrictions. These caused significant disruptions in the provision of health and education services[2,3], raising concerns about the detrimental effects it could have on vulnerable groups. We wanted to understand how these restrictions children with DS across their health, education and development; this report summarises the findings of our 2021/22 survey of the impact of the pandemic on children under 11 with DS[4,5].

What did we do?

From October 2021 to February 2022, our team of researchers at UCL partnered with Trisomy 21 Research Society and the Down Syndrome Association ran an online survey asking parents of children with DS about their child's education, healthcare access, daily routine, and physical and mental health before, during and after the COVID-19 lockdowns.

Who did we ask?

Participants were parents/caregivers of a child with DS aged 0-11 during the lockdown period (March 2020-21) that lived in the UK during the pandemic. We received a total of 241 responses to the survey from across the UK.

What did we find?

The qualitative and quantitative survey data gave us an insight into the disruptions families faced over this period. Parents reported the following impacts:

Education

- Low school attendance
- Challenges with remote learning
- Limited provision of materials and support
- Delays in return to education
- Concerns for academic progress
- Challenges returning to the classroom post-lockdown

Social and communication

- Lack of socialising affected mental health
- Increased anxiety around people
- Speech and communication development was disrupted
- Challenges with social skills post-lockdown

Daily life

- Mixed impacts on diet and sleep
- Reduction in physical activity
- Challenges managing employment and finances alongside childcare
- Disruptions affected family dynamics

Mental Health and Behaviour

- Children seemed unhappier and more anxious
- Disruptions to routine and limited social contact were seen as large contributors
- Increase in defiant and aggressive behaviour
- Challenges affected parental mental health

Physical health and development

- Increased number of health problems
- Lifestyle changes impacted weight and motor development
- Reduced number of infections overall
- Shielding resulted in delayed return to school and prolonged social distancing

Access to healthcare and support

- Delays and cancellations of routine and specialist appointments
- Continued challenges accessing care
- Limited access to developmental support
- Concerns for the long-term impacts on health and development

What does this mean?

Children with DS faced significant disruption during the pandemic and parents were already seeing impacts on their **health, education** and **development**. More research into the **longer-term effects** on families and children is needed to ensure appropriate, targeted and sustainable solutions are found.

We recommend that educators, support services, and healthcare practitioners recognise the extent and range of challenges children with DS have faced during the pandemic and the multiple ways it could affect their long-term needs. **Working with families** to develop **tailored, evidence-based** and **sustainable** solutions could help to mitigate the lack of support that was missed during the pandemic.



Introduction

"Covid has been an absolute nightmare for our family I cannot begin to explain to you"
Parent, South West England

Down syndrome (DS) is a form of neurodivergence and chromosomal condition with varying levels of intellectual abilities as well as a range of health complications, including heart defects, immune disorders, hearing and vision loss, and gastrointestinal conditions[1,6]. As such, children with DS particularly benefit from having access to a range of a support services to help them achieve optimal health and development.

Since 2020, there have been two major COVID-19 pandemic lockdowns in the UK as well as additional region-specific restrictions, causing significant disruptions to the provision of health and education services[2].

As children's health and development is affected by a range of social and environmental factors, providing appropriate developmental support across a child's support system in these years is vital to ensuring long-term health and wellbeing[7,8]. The restricted access to these vital parts of children's ecological support systems raised immediate concerns about how it would affect children in both the short and long term[8,9]. A recent COVID-19 inquiry report highlighted that the UK government failed to sufficiently consider the consequences of school closures for children's education and physical and mental health[10]; though this was a challenge all children faced, those with Special Educational Needs and Disabilities (SEND) were particularly affected by the restrictions due to the lack of access to support [11,12].

Accessing necessary support is still a challenge 5 years on; median NHS waiting time for referrals were 1.8 times higher in April 2025 than in February 2020, and children with DS face an average 2.5-year wait to access community services[13].



To get a holistic picture of the impact of these restrictions on children with DS in the UK, our team of researchers at UCL partnered with Trisomy 21 Research Society and the Down Syndrome Association to conduct a nationwide survey. This report is an overview of the descriptive findings of caregiver responses to this survey, highlighting key statistics and supporting stories drawn from content analysis of the text responses. It breaks down our results across the topics of 'Education', 'Social & communication', 'Mental Health and Behaviour', 'Daily life' and 'Health and support services' and reflects on these findings in the context of other research to provides conclusions and recommendations on how to help children with DS and their families moving forward.

What did we do?

From October 2021 to February 2022, we ran an online survey asking parents of children with DS about their child's education, healthcare access, daily routine, and physical and mental health before, during and after the COVID-19 lockdowns (Lockdown 1: March-June 2020; Lockdown 2: January-March 2021). The survey included a mix of question types, using a combination of 5-point scales, multiple choice, and free-text responses. When we designed the study, we spoke with parents of children with DS to make sure the questions were accessible and useful. We collected the descriptive statistics from the responses and content analysis of the text responses to identify supporting quotes, as well as conducting in-depth thematic analysis on parental concerns.

Who did we ask?

All participants had to be a parent/carer of a child with DS aged 0-11 (inclusive) during the lockdown period (March 2020-21) and have lived in the UK during the pandemic. We received a total of 241 responses to the survey from across the UK. Children were primarily White (n=215) and male (n=124) and lived in England (n=192) (Figure 1) with an average age of 7.5 years old as of January 2022, ranging from 1-13 years (Figure 2). All respondents were parents, except for 3 who were grandparents. For the purposes of this report, we will refer to all respondents as 'parents' or 'caregivers' interchangeably. More details can be found in Appendix 1.

Figure 1: Participant country of residence

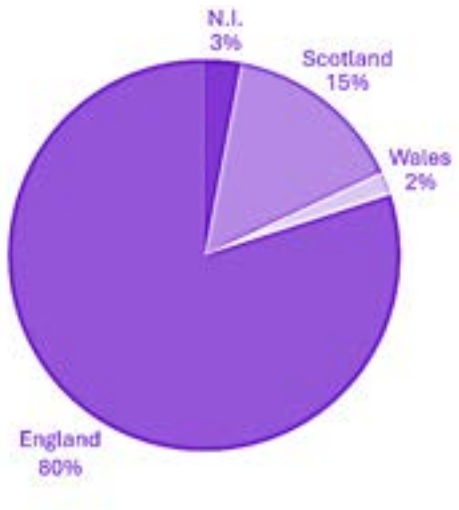
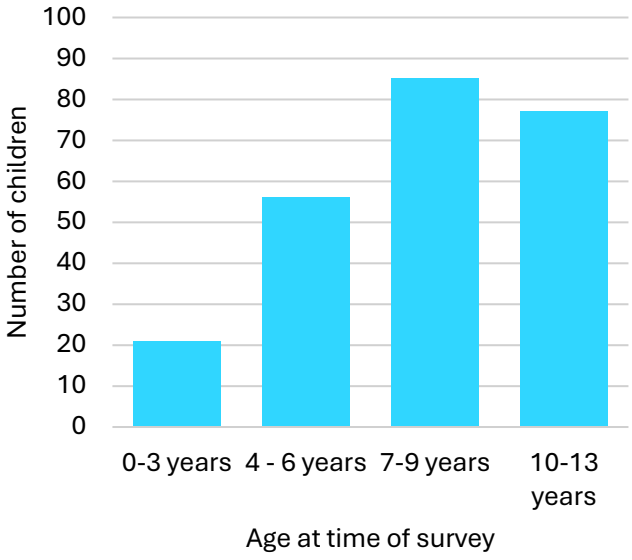


Figure 2: Participant ages

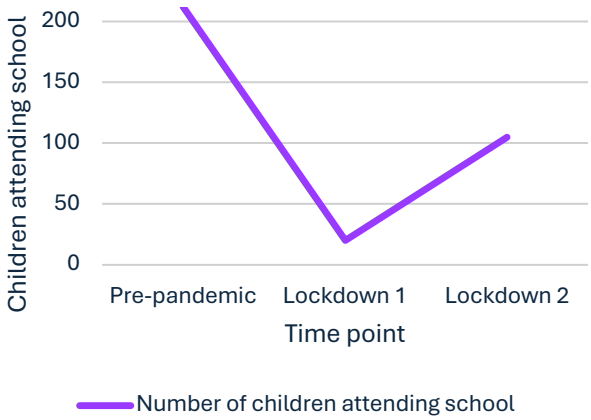


Findings

Education

Attendance

Figure 3: In person school attendance during lockdowns (n)

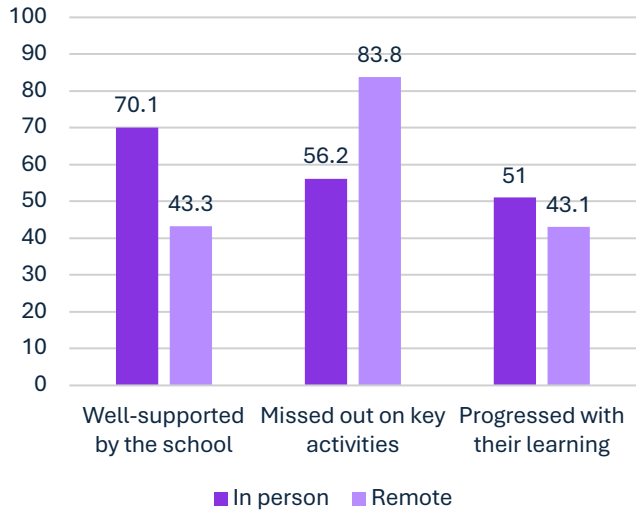


In the UK, it is common for children with DS to attend mainstream primary schools, with additional support offered where needed; 88% of children in our sample attended formal education (nursery or primary school) before the pandemic began in March 2020 (n=212). Acknowledging their need for additional developmental support, many children with DS were given the option to attend school throughout the pandemic; however, we found that during the first lockdown, 91% of children stopped attending school in person (n=192) (similar to government figures for vulnerable children overall), and less than half attended during the second lockdown (n=105; 49.8%) (Figure 3).

Remote learning & progress

Many UK schools replaced in-person teaching with online learning to prevent children getting behind on their studies. Over half of parents whose child had engaged in remote learning believed their child had progressed with their learning (n=34; 32.7%) and were more likely to feel that their child missed out on key learning activities (n=88; 86.8%) compared to parents whose children engaged in face-to-face education (n=59; 56.2%) (Figure 4). They were also less likely to feel like their children were well supported by the school (53.3% vs 70.9%); the majority of parents whose child engaged in remote education reported that it was left down to them to manage their child's learning (n=65; 61.9%).

Figure 4: Educational progress during lockdowns (% agreed)



Though remote education had its challenges, some children did not even have access to this support; parents reported that only half of children (n=106; 50.7%) who stayed home from school during lockdowns continued their education online. This was mostly due to their children not being able to concentrate on their work (n=48; 47.1%), parents sharing that

their children struggled with engaging through screens and were thrown off by the disruption to routine. However, a quarter (n=25; 24.5%) said this was because they were not provided sufficient or appropriate online resources by the school.

These responses highlighted that many parents were left in charge of a significant amount of their children's learning regardless of whether they had officially continued their studies remotely. Parents had found this challenging, especially those who were juggling it alongside working from home. This had serious consequences for some; one parent reported that they had to walk away from their business to home school their three children.

"It took all of my efforts to structure her day and teach her full time."
Parent, North West England

At the same time, some of those that had the time and resources did find that one-to-one activities had been beneficial to their child, due to the individual attention they were receiving and the ability to tailor the activities to their children's needs.

Long-term academic concerns

These challenges were a major concern for parents, who were worried about the long-term effects this would have on their education.

"My child has regressed in academia. She is not able to achieve the targets she had set 3 academic years ago which she was able to do"
Parent, Northern Ireland

Extracurricular

It is not just academic attainment that may be affected by limited educational and healthcare access. Schools are a key link to providing access to extracurricular activities that provide opportunities to develop motor, social and creative skills, yet 95% of children who had taken part in extracurricular activities before the pandemic no longer had access to these opportunities (n=153). 84% of their parents felt that this had had a moderate to large impact on their child (n=129), and shared concerns about how this had affected their health and development.

Social and communication

The development of language and social skills is vital to support other aspects of children's development, and lockdowns restricted access to support networks and social opportunities.

Social life & relationships

Social distancing restrictions meant that children couldn't see family or friends, and parents shared that their children really missed this social interaction. During the pandemic, the commonly used primary method of communication families used to socialise with people outside of their household was videocalls (n=140; 62.7%). However, despite their popularity, some parents reported that children had "*struggled to interact with people over video and phone*" (Parent, South East England), which led to some children disengaging from extended family or losing contact with friends. Some families were not socialising outside their household during lockdowns, even remotely. 17.9% of respondents (n=40) listed that they were primarily not in contact with anyone outside of their household, almost of half (n=19; 47.5%) of whom reported no other form of external communication. Some also reported that the lockdowns place pressure on family relationships, with two thirds of parents reporting that the family dynamic was more strained (n=159; 67.6%) – though others reported a positive impact (n=33; 16%) and that family time had been beneficial.

Social skills & behaviour

Over half of parents (59.8%, n=143) reported a deterioration in their child's social skills over the pandemic period. Over a third reported a change in the way children felt about interacting with others in person (n=95; 40.3%), with the most common changes being that they seemed more cautious (n=37; 40.7%) and anxious (n=30; 33%).

"My son has regressed in his ability to socialise appropriately. He has become anxious in large social gatherings."

Parent, Yorkshire

However, a few believed that social isolation had had a positive impact on their children's attitudes to socialising, saying that they seemed more excited (n=11; 12.1%) and sociable (n=4; 4.4%) once restrictions were lifted.

Language & Communication skills

Communication skills provide the foundations on which children build other key abilities. 53% of parents felt that their child's ability to communicate had changed during lockdowns; of these, 31% reported that their children's ability to communicate had deteriorated (n=39; 31%) and 40.5% that it had not progressed as expected (n=51; 40.5%). Parents felt was due to a lack of social opportunities and little developmental support. They were concerned about the long-term impacts on their children's language ability and what this meant for their overall development.

"We were moving forward with social interaction and communication but now we have gone backwards"

Parent, Northern Ireland

Mental Health and Behaviour

Our findings highlighted that the pandemic had a large impact on children's mental health. Two thirds of parents (n=161; 68.5%) reported that lockdowns had a negative impact on their child's emotional wellbeing, and over a quarter of parents (n=66; 28%) reported that their children seemed unhappy often/almost always during lockdowns - over ten times as many children as pre-pandemic (n=6; 2.5%).

Many parents attributed the low mood to feeling isolated from friends and family:

"being isolated too much from other children, family and friends caus[ed] loneliness, my child is very sociable and found this very very hard"

Parent, South East England

A fifth (n=47; 19.9%) reported that their children cried often/almost always during the lockdowns. Children expressed that they missed seeing their friends and family, concerns about germs, and that several were concerned about loved ones dying.

"During the first lockdown my son was concerned everyone was going to die"

Parent, East Midlands

This fear was not unfounded; forty-four participants reported losing a loved one during the pandemic, almost of quarter of which were due to COVID-19 (n=11; 24.4%). Over half of these parents reported that this had a direct negative impact on their child (n=25; 55.5%). It was not only fatal cases that were of concern; personal or family experiences of having COVID-19 (or even the threat of it) was a cause for fear and anxiety.

"As a family we all got Covid, and I her mother, was hospitalised for 3 days. She was very scared about me being in hospital"

Parent, North West England

Behaviour

Identifying changes in behaviour can help to indirectly assess the mental wellbeing in populations that may find it more difficult to express their feelings verbally. Parents reported children were more considerably more defiant, with over twice as many parents reporting that they child showed defiant behaviour often/almost always during lockdowns (n=128; 55.2%) than before the pandemic (n=60; 25.7%), while four times as many reported tantrums often/almost always during lockdowns (n=67; 28.6%) than previously (n=16; 6.8%).

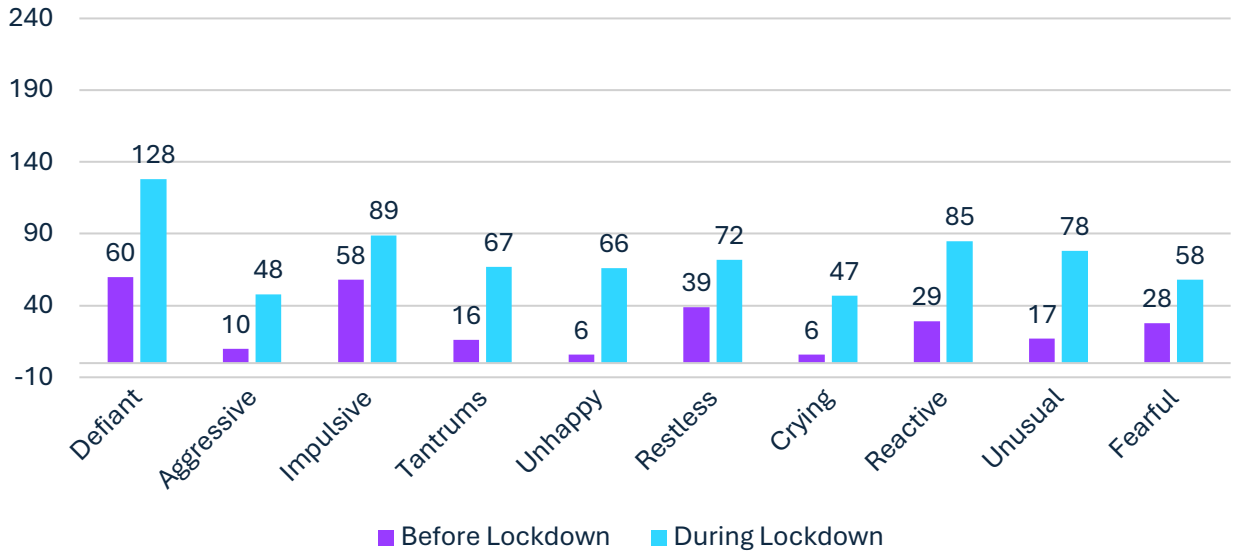
There was also an increase in aggressive behaviour, which in some cases led to children harming to themselves and others:

“he became very angry, which leads to hurting himself and other people around him such his mum and his brother.”

Parent, South East England

Parents also noticed that their children were more impulsive, reactive to stressors, wet themselves more frequently and showed increases in ‘unusual’ behaviours such as head banging (see Figure 5).

Figure 5: Number of children presenting with behaviours 'often' or 'almost always



Some also reported an increase in behavioural challenges post-lockdown when children returned to group social environments.

Despite these changes in mood and behaviour, over half of parents (n=139; 58.2%) reported that their children were ‘seemingly unaware of the pandemic’. However, some reported that the believed this lack of understanding was contributing to their poor mental health.

Daily life

Pandemic restrictions had a significant impact on daily life, and routine is particularly important to children with DS. We wanted to capture how this disruption affected family's lifestyle to provide context and identify any contributing factors to the wider health and wellbeing impacts children were facing.

Sleep

Our findings suggest that the pandemic did not have a major impact on children's sleeping patterns. There was a slight reduction in parents reporting over 7 hours sleep a night, sleep duration mostly stayed the same with most reporting 7-10 hours a night both pre (n=132; 55.9%) and during (n=124; 53%) lockdowns (Figure 6). There was also a small increase in the number of hours slept in the day (n=36; 19.9% vs n=48; 22.8%), though most reported less than one hour even during the pandemic (n=178; 77.7%) (Figure 7). Some children did have more trouble falling asleep (n=58; 25.3%) and staying asleep (n=59; 25.8%), but most did not report a difference. Most saw no change in sleepwalking and/or nightmares (n= 167; 76.6%), with similar numbers experiencing both and increase (n=25; 11.5%) and a decrease (n=26; 12%). It is worth noting that as many of our sample were experiencing the pandemic during their early years, when changes in sleep would be expected regardless.

Figure 6: Hours child slept in the night

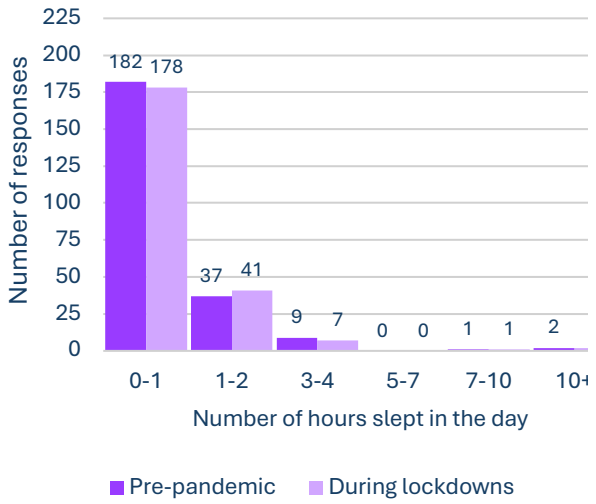
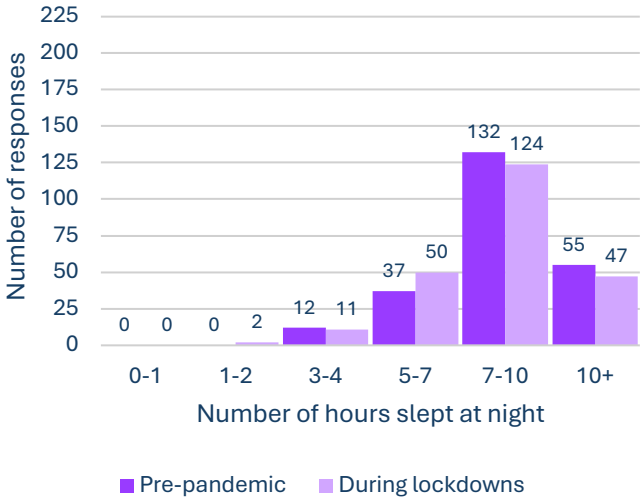


Figure 7: Hours child slept in the day



Employment & Finance

Financial insecurity also affected families with children with DS. A fifth of respondents (n=46; 19.7%) and/or their partners (n=47; 20.4%) experienced a change in employment status. Two thirds of these changes were due to being furloughed, unemployed, or having to reduce their working hours during the pandemic (n=65; 66.3%).

"My daughter was four and requires 1-1. They refused to furlough me and refused flexible home working. [...] I quit my job which was well paid to take a minimum wage job with less holiday pay and no sickness pay."

Parent, East Midlands

Even those still working were affected financially, with a third families reporting that the pandemic had had a negative impact on their household income (n=77; 33.2%). This had a negative impact on their ability to financially provide for their children, with these families struggling to pay for extracurricular activities (n=31; 40.3%), toys (n=27; 34.6%), school materials (n=12; 16.9%), transport to attend medical appointments (n=10; 12.8%), and even food (n=8; 10.4%) and heating (n=9; 11.5%).

One family even became homeless, and parents described resorting to only eating tinned foods and feeling like they had to hide their stress from their children.

"[My child] Missed out on birthday presents we ate tinned food(we put on weight) Our Internet got cut off electricity got cut off"

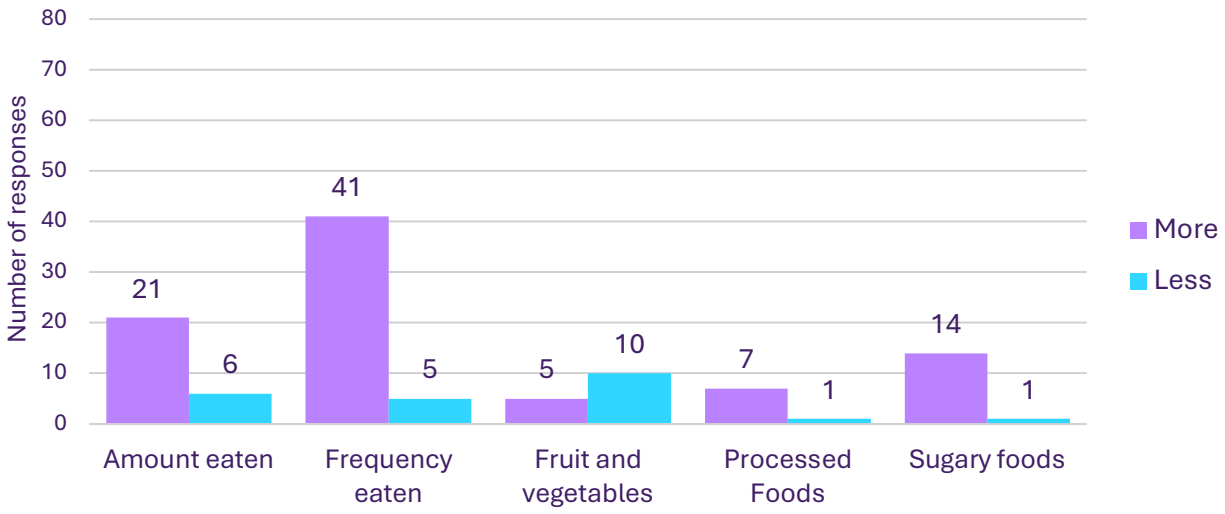
Parent, South West England

As families with children with SEND were more likely to face more financial challenges before the pandemic, considering these impacts is vital context when discussing how accessible support can be provided.

Diet

The majority of parents (n=150; 64.4%) reported that their children's diet did not change during lockdown. Those that saw a change reported an overall reduction in fruit and vegetable consumption (n=10; 12.3%), and an increase in sugary (n=14; 17.3%) and processed food (n=7; 8.6%) intake. Portion sizes were larger (n=21; 25.9%), but children were eating less frequently (n=5; 6.2%) (Figure 8). One parent reported that their child started refusing to eat at one point, attributed to the stress of the pandemic. Diet change was thought to be affected by factors such as routine changes, child preferences, and financial and time limitations.

Figure 8: Changes in eating habits during lockdown (n)



Some parents shared that these changes had their children had become more picky eaters during the time period, with one family concerned that this pattern would continue longer term:

> **"her eating habits appear to have been impacted by us limiting what we ate during the pandemic. She refuses so many foods now and it's a worry."**
>
> Parent, West Midlands

Parents also noted concerns about weight gain as a result.

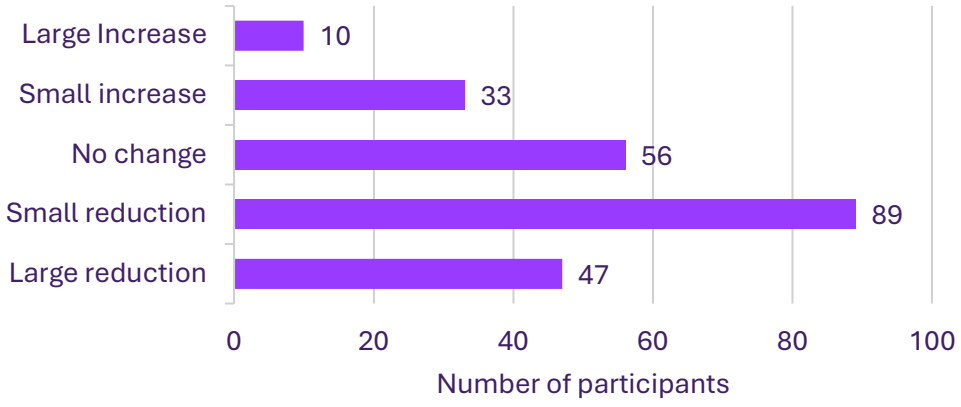
Physical Activity

Physical activity is vital for motor development, physical health, and overall wellbeing[14]. Over half of parents reported a reduction in their child's physical activity (n=136; 57.9%) and parents were concerned on the impact this had had on their children's weight and motor development (Figure 9). However, it is worth noting that some parents (n=44; 18.3%) reported an overall increase in physical activity.

Accessing green spaces (e.g., parks) is beneficial to children's health and wellbeing, and reports on children's exposure to these were also mixed. While 44% of children spent less time in green spaces (n=103; 44%), a third (n=77; 32.9%) reported an increase, perhaps due to limited access to any indoor alternatives.

Limited access to extracurricular activities contributed to these challenges. 95% of children who had taken part in extracurricular activities before the pandemic no longer had access to these opportunities (n=153) (see Education section), and this led to children missing the regular exercise that they usually had during regular team sports and swimming lessons.

Figure 9: Changes in Physical Activity levels



Children with DS often have multiple health problems that can need regular medical supervision and intervention, and parents highlighted concerns about the impact of the pandemic on their children's health needs.

Physical Health

Forty-four children were admitted to hospital over the pandemic period, and over a third of respondents (n=79; 34.5%) reported that their child had presented with an increase in non-COVID related health problems over the lockdown periods. This had a knock-on impact on their schooling, as our analysis highlighted that the greater the number of health problems that increased, the greater the delay in returning to education.

However, despite 45 children testing positive for COVID-19, almost half of parents (n=114; 49.2%) had seen a decrease in the number of infections their child had caught, perhaps due to social distancing measures and shielding.

In addition to direct medical challenges, caregivers were concerned about how the changes in lifestyle were affecting the children's health and physical development. Though lifestyle changes were universal for children during this time period, these factors are of particular concern for children with DS, who are both more prone to becoming overweight and to have conditions that are worsened by it (e.g. cardiovascular and pulmonary conditions)[15,16].

"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"

Parent, South West England

Medical Appointments

Families were unable to access the support they needed to manage this increase in health concerns. 90% of children had experienced delays and/or cancellations of medical appointments during the pandemic (n=211; 89.8%) (Figure 10).

Routine clinical appointments were the most affected, with over two thirds of participants reporting disruption (n=147; 69.7%), few able to access appointments in-person (n=34; 14.5%), and only 10% of scheduled surgeries going ahead as planned (n=4; 10.3%).

Figure 10: Disruption to medical appointments



"His paediatrician has not seen him since he was 3 months old and he is almost 3 now."

Parent, Scotland

These concerns were still an issue two years after the start of the pandemic, with several parents reporting how challenging they found it still was to get access to health care.

Support and therapy services

More than three quarters of parents reported that their child attended regular developmental support appointments before the pandemic (n=183; 81.6%). Around half of occupational health appointments (n=41; 52.6%), and almost half of physiotherapy (n=29; 45.3%) and Early Years support appointments (n=23; 47.9%) did not continue during the pandemic.

School closures contributed to this disruption, as almost two thirds of parents reported accessing regular therapies through their school pre-pandemic (n=155; 64.9%). Most of these children were not able to access this support while schools were closed (n=93; 60.4%), and over a third had their appointments moved to online (n=54; 35.1%).

Parents felt these delays had significantly impacted their children's physical, social, speech and cognitive development and were concerned about the long-term impact this could have on their child's future progress.

"[Her] development really stagnated. Her walking and talking is very delayed I think due to very little support for nearly 18 months"
Parent, South East England

Concerns about the impacts of restricted access to speech and language therapy was a prominent theme in the open text responses, and many mentioned speech or SLT services when asked for their top 3 concerns about the impact of the pandemic.

"She also hasn't had the developmental support from speech & language, physio etc to bring on her communication and mobility." Parent, Scotland

An integrated approach

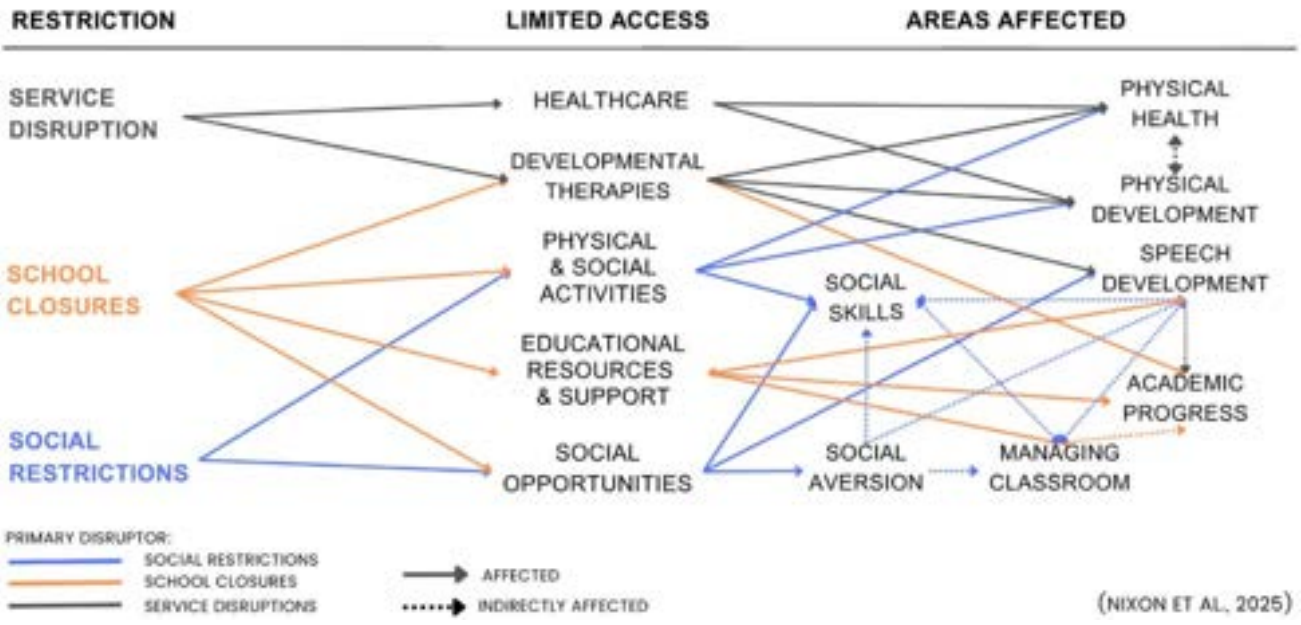
Parents reported facing challenges across all the different layers of the children's support systems that are so vital for their development. We found that the impacts of the pandemic disruption to educational, daily life, and health and support services also had interconnected impacts.

For example, a lack of access to school resources affected children beyond just impacting their education. It limited access to support services, extracurricular activities and social opportunities, which parents reported had impacts across health, development and wellbeing. There are also longer-term impacts of educational performance to consider, as academic attainment in school can predict long-term health and wellbeing[17]. Health challenges, in turn, can limit access to education; generalised mixed modelling of school attendance and reported health problems revealed that experiencing an increase in health problems during the COVID-19 pandemic predicted a reduction of time in education for participants in England, and that this had a cumulative effect (see Appendix 3).

As part of our more in-depth analysis of parents' text responses, we mapped out the parent-reported impacts of the pandemic restrictions and the mechanisms through which they were affected[5] (Figure 11). This figure highlights how interconnected all the factors are, and looking at each in isolation only allows for a 'band aid' solution. For an in-depth look at these challenges, see our paper in the British Journal of Special Education[5].

These findings highlight the importance of assessing the needs of children with DS holistically and encouraging collaboration across services to provided tailored integrated care.

Figure 11: Perceived impact of the pandemic restrictions on children with Down Syndrome



Discussion

This study has given an insight into the daily lives and experiences of children with DS during the pandemic in the UK, and the potential concerns for the ongoing impacts. The report has highlighted the key descriptive statistics and responses shared by caregivers of children with DS, who witnessed firsthand how the pandemic has affected their children's wellbeing. It highlighted how disruptions to support systems created multiple, intersecting challenges for children with DS and their families, with potentially lifelong implications for their health, education and development.

Daily life and routine were affected, but the way that they were impacted varied from household to household. The social and developmental concerns that were touched upon in these findings were a major worry for parents. Education and health were the most disrupted with pandemic restrictions, and the long-term consequences that this could have on their development are something that will need to be considered moving forward.

There were large impacts, but as they affected children in different ways (i.e., increases and decreases), we could only identify one significant correlation when we conducted exploratory analyses – the link between the number of health problems that increased and a delay in returning to school (Appendix 3). This highlights the complexity of the ways pandemic affected families and the unique variations between children with DS.

Recommendations

> **"I already feel like 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"**
> Parent, South East

Our findings provide context that can inform the basis of how policymakers, healthcare and support professionals, educators and academics approach engaging and supporting families with children with DS moving forward. Continuing to acknowledge these challenges is vital as children still face significant delays in accessing services and support. Many local authorities in the UK are currently facing financial limitations, meaning that funding for health, education and support resources are limited[18]. However, investing in early intervention and preventative initiatives can prevent future health and wellbeing challenges across the life course[19,20]. Making sure that support is sufficiently available across health, education and development could not only improve quality of life of people with DS in the short term, but could have lifelong individual, societal and economic benefits, including the reduction in future demand for health and support services[17,19,21]. As part of the government's



reassessment of how their policies can be more disability-inclusive, **we suggest that working with families** to develop and invest in **tailored, evidence-based** and **sustainable** solutions that acknowledge the impacts of the pandemic could help to mitigate any damage caused by the lack of support families experienced.

Provide targeted and integrated care

Policymakers and local authorities should recognise the importance of investing in holistic childhood SEND support. Practitioners and educators should consider the impact that the pandemic and other a child's holistic needs and context when assessing and treating children with DS. Children with DS are facing an average 2.5-year wait to access community services[13], so when they are able to engage with a practitioner it is key that they are getting targeted and effective advice.

Support and engage with families

When looking to support children with DS, consider the needs of the whole family. Our survey did not ask about caregiver mental health directly, but parents shared some of their personal struggles in the open text responses. They found managing their child's health, education and developmental needs challenging and emotionally draining, and were concerned about how their personal struggles would affect their children. As parental mental health provides benefits to the whole family, it is key to empower parents to feel more confident in managing their children's needs when support is not available. Collaboration with parents when designing and delivering services could help to make services more accessible to families.

Support academic progress

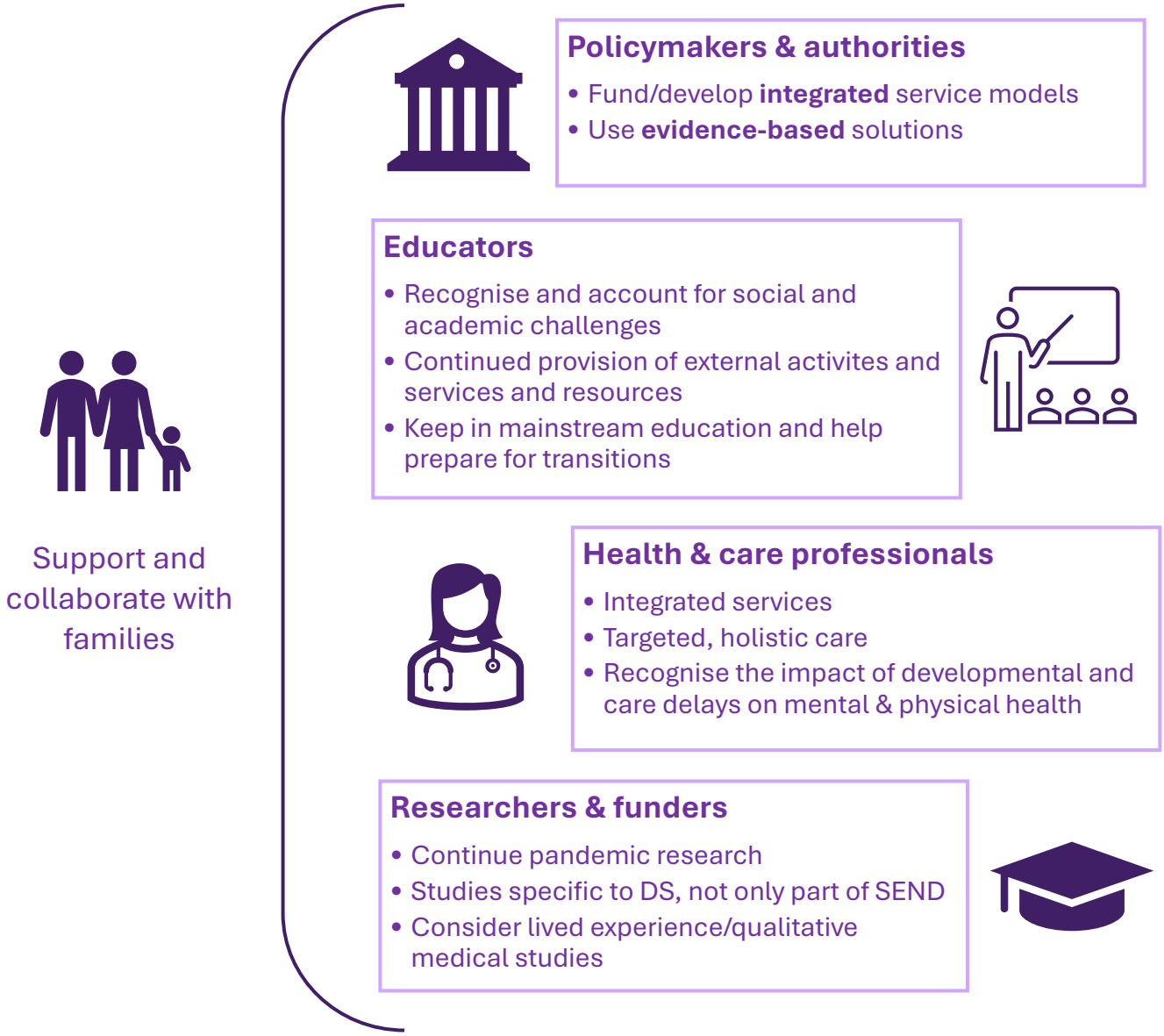
The significant disruption to education may mean that children with DS need extra time and support to catch up with peers. We recommend educators and care services avoid assuming children's academic and developmental potential based on pre-pandemic milestones or write off their capabilities due to their SEND status. The pandemic has also emphasised the additional benefits that staying in mainstream schooling provides for children with DS (e.g., social connection, activities), so we suggest keeping them in formal education where possible. Many of this cohort will have been transitioning from primary to secondary education since lockdowns, something that was already particularly challenging for children with DS[22]. Ensuring that children that had such a significant amount of their early years in lockdown are ready for this transition could help to mitigate further academic, health and wellbeing challenges down the line.

Research the long-term impacts on children with DS

We encourage researchers to build on the findings of this report with further investigations; understanding the longer-term impacts of lockdowns on children's health, education, and development, and what parents and children think would help to mitigate these challenges will help to provide more effective support. There has been a decline in paediatric DS health research over the last decade, and studies using mixed-methods and detailing lived experience

are limited[23]. To enable academics to action these projects, research councils need to acknowledge the continued relevance of pandemic-related projects to children's health and wellbeing.

Figure 12: Recommendations



Conclusions

The COVID-19 Inquiry highlighted some key flaws in the current way that Disabled groups are - or are not – considered in public health policy, and this report provides evidence that this extends to children with DS. The continued impacts across children's development, particularly children with SEND, is still a significant concern; acknowledging the impact of experiencing the pandemic in the early years of development needs to continue being a necessary part of the conversation about how to support children and young people for years to come. We hope that these findings provide a much-needed insight into the lives of children with DS and can provide evidence to help guide policymakers, educators and healthcare professionals on how to support them as they work to build more inclusive systems.

References

1. Centers for Disease Control and Prevention. Living with Down Syndrome. 2024. Accessed April 22, 2025. https://www.cdc.gov/birth-defects/living-with-down-syndrome

2. UK Government. Timeline of UK government coronavirus lockdowns and restrictions. 2022. Accessed April 22, 2025. https://www.instituteforgovernment.org.uk/data-visualisation/timeline-coronavirus-lockdowns

3. UK Government. Attendance in education and early years settings during the coronavirus (COVID-19) pandemic. 2022. Accessed April 22, 2025. https://explore-education-statistics.service.gov.uk/find-statistics/attendance-in-education-and-early-years-settings-during-the-coronavirus-covid-19-outbreak/2022-week-30

4. Nixon L, Milla de la Fuente G, Costanzo F, Sideropoulos V, Van Herwegen J, Lakhanpaul M. The impact of the pandemic on children under 11 with Down Syndrome. *Arch Dis Child*. 2022;107(Suppl 2):A318-A319.

5. Nixon L, de la Fuente GM, Sideropoulos V, Lakhanpaul M. 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. *British Journal of Special Education*. Published online July 9, 2025.

6. Thapar A, Cooper M, Rutter M. Neurodevelopmental disorders. *Lancet Psychiatry*. 2017;4(4):339-346.

7. Bronfenbrenner U. Toward an experimental ecology of human development. *American Psychologist*. 1977;32(7):513-531.

8. Egan SM, Pope J. A Bioecological Systems Approach to Understanding the Impact of the COVID-19 Pandemic: Implications for the Education and Care of Young Children. *Educating the Young Child*. 2022;18:15-31.

9. Egan SM, Pope J, Moloney M, Hoyne C, Beatty C. Missing Early Education and Care During the Pandemic: The Socio-Emotional Impact of the COVID-19 Crisis on Young Children. *Early Child Educ J*. 2021;49(5):925-934.

10. UK Covid-19 Inquiry. *UK Covid-19 Inquiry Modules 2, 2A, 2B, 2C: Core Decision-Making and Political Governance Volume 1*. 2025. Accessed January 18, 2026. https://covid19.public-inquiry.uk/wp-content/uploads/2025/11/18102043/1435-HH-E03296643_UK-Covid-19-M2-%E2%80%A2V1%E2%80%A2-Inquiry_Volume-I_accessible.pdf

11. Department of Education. *SEND Review - Right Support, Right Place, Right Time*. 2022. Accessed April 23, 2025. http://www.education.gov.uk/contactus.

12. Benhenda A. Briefing note: Post-pandemic funding for SEND pupils: is it enough? Published online 2022. Accessed from cepeobn16.pdf.

13. Children's Commissioner. Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions. Published online 2024. Accessible at https://assets.childrenscommissioner.gov.uk/wpuploads/2025/05/cco-childrens-mental-health-annual-briefing-may-2025.pdf

14. Theis N, Campbell N, De Leeuw J, Owen M, Schenke KC. The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. *Disabil Health J*. 2021;14(3):101064. doi:10.1016/J.DHJO.2021.101064

15. Bertapelli F, Pitetti K, Agiovlasitis S, Guerra-Junior G. Overweight and obesity in children and adolescents with Down syndrome-prevalence, determinants, consequences, and interventions: A literature review. *Res Dev Disabil*. 2016;57:181-192. doi:10.1016/J.RIDD.2016.06.018

16. Capone GT, Chicoine B, Bulova P, et al. Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. *Am J Med Genet A*. 2018;176(1):116-133. doi:10.1002/AJMG.A.38512

17. WHO Regional Office for Europe. *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health*. 2008.

18. The Guardian. Nearly 20 councils in England 'at risk of insolvency' due to Send costs | Special educational needs. 2025. Accessed April 22, 2025. https://www.theguardian.com/education/2025/mar/30/councils-england-insolvency-risk-send-costs

19. Marmot M, Bell R. Social determinants and non-communicable diseases: time for integrated action. *BMJ*. 2019;364. doi:10.1136/BMJ.L251

20. World Health Organisation. *World Report on Social Determinants of Health Equity: Executive Summary*. 2025. Accessed February 2, 2026. https://www.who.int/publications/i/item/B09387

21. Kirkbride JB, Anglin DM, Colman I, et al. The social determinants of mental health and disorder: evidence, prevention and recommendations. *World Psychiatry*. 2024;23(1):58-90. doi:10.1002/WPS.21160

22. Sideropoulos, V., Palikara, O., Burchell, E., Ashworth, M., & Van Herwegen, J. Anxiety during transition from primary to secondary schools in neurodivergent children. *JCPP Advances*. 2024; 5(2), e12262. https://doi.org/10.1002/jcv2.12262

23. McKenna, C., Schilder, A., Lee, R. X. N., Manikam, L., Venekamp, R., & Lakhanpaul, M. Mapping two decades of paediatric down syndrome research literature. *The Ulster medical journal*. 2023; 92(2), 77-83.

Appendices

Appendix 1: Participant Characteristics

Category	Subcategory	No. of respondents	Percentage of respondents
Gender			
	Male	123	51.7%
	Female	115	48.3%
Ethnicity			
	Asian/Asian British	2	0.8%
	Black/Black British	1	0.4%
	Mixed/Multiple Ethnic Groups	20	8.4%
	White	212	89.1%
	Prefer not to say	1	0.4%
	No answer	2	0.8%
Country of residence			
	England	191	80.3%
	Wales	5	2.1%
	Scotland	35	14.7%
	Northern Ireland	7	2.9%
Household composition			
	Both parents, same household	193	81.1%
	Both parents, separate households	4	1.7%
	Single parent	21	8.8%
	Extended family	20	8.4%

Appendix 2: Summary table of results

Education

Items	Response	Frequency (n)	Percent (%)	Total	Missing
Attended school or nursery face to face pre-pandemic	Yes	212	88	241	0
	No, they are not in formal education	25	10.4		
	No, they are home schooled	4	1.7		
Attended face-to-face education in Lockdown 1	Yes	19	9	208	33
	No	192	91		
Attended face-to-face education in Lockdown 2	Yes	105	49.8	201	30
	No	106	50.2		
Child was well supported (while attending face to face education in lockdowns)	Strongly disagree	8	7.8	103	138
	Disagree	13	12.6		
	Indifferent	9	8.7		
	Agree	42	40.8		
	Strongly Agree	31	30.1		
Child engaged more with their learning (while attending face to face education in lockdowns)	Strongly disagree	17	16.5	103	138
	Disagree	17	16.5		
	Indifferent	25	24.3		
	Agree	18	17.5		
	Strongly Agree	26	25.2		
Child progressed with their learning (while attending face to face education in lockdowns)	Strongly disagree	11	10.5	102	139
	Disagree	15	14.3		

	Indifferent	20	19		
	Agree	33	31.4		
	Strongly agree	26	24.8		
Child missed out on key learning activities (while attending face to face education in lockdowns)	Strongly disagree	11	10.5	105	136
	Disagree	15	14.3		
	Indifferent	20	19		
	Agree	33	31.40		
	Strongly Agree	26	24.80		
Engaged in remote learning	Yes	106	50.7	209	32
	No	103	49.3		
How children who engaged in remote learning were primarily educated	Online (parent led)	65	61.9	105	136
	Online (school led)	22	21		
	Online & face to face	18	17.1		
Child was well supported (while engaging with remote education)	Strongly disagree	17	16.3	104	137
	Disagree	20	19.2		
	Indifferent	22	21.2		
	Agree	39	37.5		
	Strongly Agree	6	5.8		
Child engaged more with their learning (while engaging with remote education)	Strongly disagree	31	30.1	104	137
	Disagree	36	35		
	Indifferent	20	19.4		
	Agree	13	12.6		
	Strongly Agree	3	2.9		
	Strongly disagree	22	21.2	104	137

Child progressed with their learning (while engaging with remote education)	Disagree	31	29.7		
	Indifferent	17	16.3		
	Agree	29	27.9		
	Strongly agree	5	4.8		
Child missed out on key learning activities (while engaging with remote education)	Strongly disagree	8	7.6	105	136
	Disagree	4	3.8		
	Indifferent	5	4.8		
	Agree	53	50.5		
	Strongly Agree	35	33.3		
Reasons why children did not continue their education online	Resources not provided by school	25	24.5	102	139
	No electronic device to use	1	1		
	No internet	0	0		
	Could not concentrate	48	47.1		
	Other	28	27.5		

Social and Communication

Items	Response	Frequency (n)	Percent (%)	Total (n)	Missing (n)
	Yes	127	53.6	237	4

Children's whose ability to communicate changed during lockdown	No	110	46.4		
Impact of lockdowns on children's communication	Deteriorated	39	30.9	126	115
	No progressed as expected	51	40.5		
	Improved	36	28.6		
Changes to children's social skills	Large deterioration	44	18.4	239	2
	Small deterioration	99	41.4		
	No change	75	31.4		
	Small improvement	14	5.9		
	Large improvement	7	2.9		
Children affected by the way they interacted with people outside their household during lockdowns	Yes	152	64.1	237	4
	No	85	35.9		
Children who seem to feel differently about interacting with others in person post-lockdowns	Yes	95	40.3	236	5
	No	141	59.7		

How children feel differently about interacting with others in person (most common reaction).	Cautious	37	40.7	91	150
	Anxious	30	33		
	Angry	0	0		
	Afraid	2	2.2		
	Excited	11	12.1		
	Sociable	4	4.4		
	Other	7	7.7		
Children who communicated (e.g. talk, gestures, sign language) with parents about the pandemic	Yes	45	88.3	51	190
	No	6	11.8		
Changes in family dynamic during lockdowns	Became much more strained/stressful	79	33.6	235	6
	Became a little more strained/stressful	80	34		
	Stayed the same	28	11.9		
	Became a little more relaxed	42	17.9		
	Became a lot more relaxed	6	3.2		
	Became much more strained/stressful	79	33.6		
	Very negatively	19	9.2	206	35
	Moderately negatively	88	42.7		

How child was affected by change of family dynamic	No impact	66	32
	Moderately positively	27	13.1
	Very positively	6	2.9

Mental Health & Behaviour

Item	Response	Frequency (n)	Percent (%)	Total (n)	Missing (n)
Child's diagnosed psychological conditions	None	184	86.4	213	28
	Anxiety	4	1.9		
	Depression	1	0.5		
	Motor disorders	3	1.4		
	Adjustment Disorder	0	0		
	Post-traumatic Stress Disorder	0	0		
	ADHD	3	1.4		
	Obsessive Compulsive Disorder	0	0		
	Oppositional Defiant Disorder	0	0		
	Autism Spectrum Disorder	14	6.6		
	Other	9	4.2		
Child experienced the end of a life of a loved one	Yes (due to COVID-19)	11	4.7	235	6
	Yes (not related to COVID-19)	34	14.5		
	No	190	80.9		

How losing a loved on affected child	Very negatively	6	13.3	45	196		
	Moderately negatively	19	42.2				
	No impact	19	42.2				
	Moderately positively	1	2.2				
	Very positively	0	0				
How concerned children seemed to be about the pandemic	Very concerned	8	3.3	239	2		
	Moderately concerned	44	18.4				
	Neutral	20	8.4				
	Not concerned	28	11.7				
	Seeming unaware of the pandemic	139	58.2				
Change in child's emotional state during lockdowns	Large deterioration	27	11.5	235	6		
	Moderate deterioration	55	23.4				
	Small deterioration	79	33.6				
	No change	62	26.4				
	Small improvement	8	3.4				
	Moderate improvement	3	1.3				
	Large improvement	1	0.4				

Item	Response	(n)	(%)	(n)	(%)	Total (n)	Missing (n)

		Pre-lockdowns		During lockdown			
How often child was reactive to stressors pre lockdown	Never	49	20.9	43	18.3	235; 235	6; 6
	Rarely	68	28.9	37	15.7		
	Occasionally	89	37.9	70	29.8		
	Often	27	11.5	67	28.5		
	Almost always	2	0.9	18	7.7		
How often child cried	Never	81	34.3	62	26.3	236;236	5; 5
	Rarely	94	39.8	73	30.9		
	Occasionally	55	23.3	54	22.9		
	Often	6	2.5	41	17.4		
	Almost always	0	0	6	2.5		
How often child seemed afraid pre - lockdowns	Never	54	23	51	21.9	235;233	6;8
	Rarely	81	34.5	57	24.5		
	Occasionally	72	30.6	67	28.8		
	Often	25	10.6	44	18.9		
	Almost always	3	1.3	14	6		
How often child seemed unhappy	Never	38	16.1	19	8.1	236; 236	5; 5
	Rarely	126	53.4	75	31.8		
	Occasionally	66	28	76	32.2		
	Often	6	2.5	59	25		

	Almost always	0	0	7	3		
How often child presented with "unusual" behaviours (e.g., head-banging)	Never	55	23.4	46	19.7	235;234	6;7
	Rarely	94	40	51	21.8		
	Occasionally	69	29.4	59	25.2		
	Often	16	6.8	62	26.5		
	Almost always	1	0.4	16	6.8		
How often child had tantrums	Never	31	13.2	27	11.5	235; 235	6;6
	Rarely	110	46.8	62	26.4		
	Occasionally	78	33.2	79	33.6		
	Often	16	6.8	53	22.6		
	Almost always	0	0	14	6		
How often child was restless	Never	47	20	43	18.4	235; 234	6;7
	Rarely	85	36.3	71	30.3		
	Occasionally	64	27.2	48	20.5		
	Often	36	15.3	54	23.1		
	Almost always	3	1.3	18	7.7		
How often child was impulsive	Never	36	15.5	32	13.8	232; 232	9;9
	Rarely	68	29.3	52	22.4		
	Occasionally	70	30.2	59	25.4		

	Often	49	21.1	66	28.4		
	Almost always	9	3.9	23	9.9		
How often child was aggressive	Never	79	33.8	62	26.7	234; 232	7;9
	Rarely	92	39.3	63	27.2		
	Occasionally	53	22.6	59	25.4		
	Often	10	4.3	36	15.5		
	Almost always	0	0	12	5.2		
How often child isolated themselves	Never	78	33.3	64	27.4	234; 234	7;7
	Rarely	80	34.2	57	24.4		
	Occasionally	63	26.9	59	25.2		
	Often	10	4.3	46	19.7		
	Almost always	3	1.3	8	3.4		
How often child wet themselves during the day	Never	71	33	65	30.4	215; 214	26; 27
	Rarely	53	24.7	44	20.6		
	Occasionally	34	15.8	37	17.3		
	Often	27	12.6	37	17.3		
	Almost always	30	14	31	14.5		
How often child was defiant pre-lockdowns	Never	18	7.7	13	5.6	233; 232	8;9
	Rarely	64	27.5	40	17.2		

Occasionally	91	39.1	51	22
Often	49	21	102	44
Almost always	11	4.7	26	11.2

Health & Appointments

Item	Response	Frequency (n)	Percent (%)	Total (n)	Missing (n)
Health problems that increased during the pandemic	No increase in health issues	150	65.8	228	13
	Vision problems	9	3.9		
	Trouble recalling recent events	2	0.9		
	Daytime Sleepiness	4	1.8		
	Fatigue	12	5.3		
	Hearing loss	14	6.1		
	Gum disease and/or dental problems	9	3.9		
	Persistent headaches	1	0.4		
	Digestive problems	16	7		
	Less physical activity or exercise	59	25.9		
	Other	9	3.9		
Child admitted to hospital (for any reason)	Yes	45	19.3	233	8
	No	188	80.7		
Medical appointment disruptions	Cancelled	32	13.6	235	6

	Delayed	88	37.4		
	Both	91	38.7		
	No	24	10.2		
Medical appointments that were disrupted (select all that apply)	GP appointment/referral	28	13.3	211	30
	Hospital appointment	86	40.8		
	Routine Clinic appointment	147	69.7		
	Health visitor	17	8.1		
	School nurse	7	3.3		
	Immunisation	7	3.3		
	Developmental review	98	46.4		
	Other	29	13.7		
How health appointments were accessed	Face-to-face	34	14.5	235	6
	Virtually	96	40.9		
	Over the phone	76	32.3		
	N/A	29	12.3		
Child awaiting surgery pre-pandemic	Yes	39	16.9	231	10
	No	192	83.1		
Planned surgeries went ahead as planned	Yes	4	10.3	39	202
	Went ahead, but delayed	17	43.6		

	No (due to pandemic)	17	43.6		
	No (for other reasons)	1	2.6		
Concern about the impact of surgery delays on child's health	Very worried	2	5.7	35	206
	Moderately worried	18	51.4		
	Not at all worried	15	42.9		
Regular appointments accessed pre-pandemic	Occupational therapy	78	34.8	224	17
	Early years support	48	21.4		
	Physiotherapy	64	28.6		
	Psychological therapies	9	4		
	Other	119	53.1		
	Not applicable	41	18.3		
Access to physiotherapy appointments during the pandemic	Continued regularly in person	1	1.6	64	177
	Continued irregularly in person	11	17.2		
	Did not continue	29	45.3		
	Continued regularly online	7	10.9		
	Continued irregularly online	16	25		
Access to occupational therapy appointments during the pandemic	Continued regularly in person	0	0	78	163
	Continued irregularly in person	18	23.1		
	Did not continue	41	52.6		

	Continued regularly online	7	9		
	Continued irregularly online	12	15.4		
Access to psychological appointments during the pandemic	Continued regularly in person	0	0	9	232
	Continued irregularly in person	0	0		
	Did not continue	6	66.7		
	Continued regularly online	1	11.1		
	Continued irregularly online	2	22.2		
Access to Early Years support during the pandemic	Continued regularly in person	1	2.1	48	193
	Continued irregularly in person	5	10.4		
	Did not continue	23	47.9		
	Continued regularly online	11	22.9		
	Continued irregularly online	8	16.7		
Access to "other" appointments during the pandemic	Continued regularly in person	4	3.4	119	122
	Continued irregularly in person	26	21.8		
	Did not continue	54	45.3		
	Continued regularly online	11	9.2		
	Continued irregularly online	24	20.2		
COVID-19					
Child tested positive for COVID-19	Yes	45	19.4	232	9
	No, they tested negative	119	51.3		

	No, they were not tested	68	29.3		
Children isolated due to exposure to COVID-19 or COVID-19 diagnosis	Yes	129	54.9	235	6
	No	106	45.1		
How COVID-19 isolation impacted child	Very negatively	19	14.8	128	113
	Moderately negatively	58	45.3		
	No impact	48	37.5		
	Moderately positively	2	1.6		
	Very positively	1	0.8		
Child received medical treatment for severe COVID-19	Yes	6	13.3	45	196
	No	39	86.7		

Daily life

Item	Response	Frequency (n)	Percent (%)	Total (n)	Missing (n)
Child's eating habits changed	Yes	83	35.6	233	8
	No	150	64.4		
How children's eating habits changed	Ate more often	41	63	81	160
	Ate less often	5	6.2		
	Bigger amounts of food	21	25.9		
	Smaller amounts of food	6	7.4		
	More fruits and vegetables	5	6.2		
	Less fruits and vegetables	10	12.3		
	More processed foods	7	8.6		
	Less processed foods	1	1.2		
	More sugary foods	14	17.3		
	Less sugary foods	1	1.2		
	Other	9.9			
Employment and Finance					
	Became unemployed	12	26.1	46	195

Caregiver 1 employment status changes during lockdown	Reduced hours of work	9	19.6		
	Became furloughed	7	15.2		
	Started new job	9	19.6		
	Retired	0	90		
	Other	14	30.4		
Caregiver 1 had a change in employment status	Yes	46	19.7	234	7
	No	188	80.3		
Caregiver 2 employment status changes during lockdown	Became unemployed	13	27.7	52	189
	Reduced hours of work	5	10.6		
	Became furloughed	19	40.4		
	Started new job	7	14.9		
	Retired	0	0		
	Other	8	17		
Caregiver 2 had a change in employment status	Yes	47	20.4	230	11
	No	183	79.6		
Pandemic had a negative effect on household income	Yes	78	33.2	235	6
	No	157	66.8		

Families whose household income had been negatively affected struggled to pay for:

Transport to medical appointments	Yes	10	12.8	78	163
	No	68	87.2		
Transport to school/nursery	Yes	3	4.2	71	170
	No	68	95.8		
Toys for their child	Yes	27	34.6	78	163
	No	51	65.4		
School materials	Yes	12	16.9	71	170
	No	59	83.1		
Extracurricular activities	Yes	31	40.3	77	164
	No	46	59.7		
Food for their child	Yes	8	10.4	77	164
	No	69	89.6		
Heating	Yes	9	11.5	78	163
	No	69	88.5		

Became homeless/moved to temporary housing	Yes		1	1.3	78	163
	No		77	98.7		

SLEEP

Item	Response	Frequency (n)	Percent (%)	Total (n)	Missing (n)
Difficulties falling asleep (during lockdowns)	Large reduction	8	3.5	229	12
	Small reduction	7	3.1		
	No difference	156	68.1		
	Small increase	39	17		
	Large increase	19	8.3		
Difficulties staying asleep (during lockdowns)	Large reduction	7	3.1	229	12
	Small reduction	8	3.5		
	No difference	155	67.7		
	Small increase	43	18.8		
	Large increase	16	7		
Waking up earlier than usual (during lockdowns)	Large reduction	7	3.1	227	14
	Small reduction	7	3.1		
	No difference	143	63		
	Small increase	48	21.1		

	Large increase			22	9.7		
Sleepwalking, nightmares and/or sleep terrors (during lockdowns)	Large reduction			13	6	218	23
	Small reduction			13	6		
	No difference			167	76.6		
	Small increase			20	9.2		
	Large increase			5	2.3		
		Pre-pandemic		**During lockdowns**			
		n	**%**	**n**	**%**		
Number of hours slept at night						236; 234	5;7
	0-1	0	0	0	0		
	1-2	0	0	2	0.9		
	3-4	12	5.1	11	4.7		
	5-7	37	15.7	50	21.4		
	7-10	132	55.9	124	53		
	10+	55	23.3	47	20.1		
Number of hours slept during the day	0-1	182	78.8	178	77.7	231; 229	10;12
	1-2	37	16	41	17.9		
	3-4	9	3.9	7	3.1		
	5-7	0	0	0	0		

7-10	1	0.4	1	0.4	
10+	2	0.9	2	0.9	

DAILY ACTIVITY					
Amount of physical activity	Large reduction	47	20	235	6
	Small reduction	89	37.9		
	No change	56	23.8		
	Small increase	33	14		
	Large increase	10	4.3		
Amount of time playing inside the house	Large reduction	9	3.8	234	7
	Small reduction	15	6.4		
	No change	51	21.8		
	Small increase	70	29.9		
	Large increase	89	38		
Amount of time playing outside the house	Large reduction	46	19.7		
	Small reduction	69	29.5		
	No change	53	22.6		
	Small increase	41	17.5		
	Large increase	25	10.7		

Amount of time spent in green spaces (e.g., parks)	Large reduction	42	17.9	234	7
	Small reduction	61	26.1		
	No change	54	23.1		
	Small increase	56	23.9		
	Large increase	21	9		
Ability to participate in daily physical activities	Large reduction	42	17.9	235	6
	Small reduction	65	27.7		
	No change	80	34		
	Small increase	35	14.9		
	Large increase	13	5.5		

Appendix 3: Relationship between cumulative health problems and school attendance before and during COVID-19 lockdowns in England

We examined the relationship between cumulative health problems presenting in children with DS during the pandemic and their school attendance before and during the first and second COVID-19 lockdowns in England. We hypothesised that the lowest attendance (including remotely) would be during Lockdown 1, followed by Lockdown 2, and that this could be connected to perceived ill health.

Participants whose school-aged children had attended formal face-to-face education in England before the pandemic were identified (n=151). Of these, the number of hours the children spent in education per week before the pandemic, during Lockdown 1, and during Lockdown 2 were noted, as well as whether they continued their education remotely. Cumulative health problems were defined based on the total number of health problems (Vision problems; Trouble recalling recent events; Daytime sleepiness; Fatigue; Hearing loss; Gum disease/dental problems; Persistent headaches; Digestive problems; Less physical activity or exercise; Other; or no increase in health issues) for which parents reported an increase during the pandemic. Each problem added +1 to the total of the variable. We ran two models of Repeated Measures ANOVA using SPSS; the first model focused on Time x School Attendance (Hours) and the second, using the newly developed compositive variable, focused on Time X School Attendance (Yes/No) + Cumulative Health Problems During COVID-19.

Results

The data show that most school-aged children with DS were attending school face-to-face before the COVID-19 pandemic (96.02%, n=145). This, however, changed over the first lockdown in England, with only 8.966% (n=13) reporting that their child continued attending school in person. As for Lockdown 2, we can see that while many more engaged in face-to-face education (54.48%, n=79), 45.5%% (n=66) did not. 50.6% (n=73) of parents said that their children did not receive any education remotely while not at school, and 54.28% (n=38) of those who did report that their remote education was parent-led. Only 24% (n=17) of parents whose child continued school online agreed that their child's learning progressed and 86% (n=61) felt their child was missing out on key learning activities.

Generalised mixed modelling revealed that experiencing an increase in health problems predicted a reduction of time in education, and that this had a cumulative effect. Our first ANOVA model on the effect of time on duration of school attendance (hours spent in education) revealed that there was a significant effect. Mauchly's Test of Sphericity indicated that the assumption of sphericity had not been violated: $\chi 2(2) = .848$, $p = .654$. Therefore, the F statistic was accurate and no adjustment of the degrees of freedom was needed; $F(2,24)=16.179$,

p=.001, η2=.545. This confirms the findings in the descriptive statistics that children with DS spent less time in schools during Lockdown 1 than Pre-pandemic and during Lockdown 2.

Our second ANOVA model examined the effect of cumulative health problems on school attendance over time (Pre-pandemic, Lockdown 1 and Lockdown 2) and was significant across the board. However, Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated: $\chi2(2) = 50.333$, $p = .001$. Therefore, the Huynh-Feldt adjustment for degrees of freedoms was used ($\varepsilon = .772$). This revealed a significant effect of time, $F(1.543, 221.986) = 48.414$, $p = .001$, $\eta2 = .159$. However, our analysis showed no effect of cumulative health problems, $F(6,138) = 2.2079$, $p = .059$, $\eta2 = .029$ and no interaction between Time and Cumulative Health Problems, $F(9.260, 212.986 = 1.846$, $p = .060$, $\eta2 = .036$. Figure 12 presents how school attendance changed over time in relation to cumulative health problems of children with DS, showing a direct inverse association between the number of symptoms that increased in frequency and the time the child spent in education. Bonferroni post-hoc statistics revealed a significant difference between attendance during pre-pandemic and Lockdown 1, $t(9.839)$, p=.001, for pre-pandemic and Lockdown 2, $t(4.787)$, p=.001 as well as a difference between Lockdown 1 vs Lockdown 2, $t(-5.052)$, p=.001.

Figure 12: School attendance over time in relation to number of worsening health problems

