Children with Down Syndrome in Lockdown



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

Children with Down syndrome were disproportionately affected by the lockdown restrictions. We surveyed **241 parents of children with Down syndrome in the UK** to understand what life was like for their children during the pandemic and the impact it had on their **health, education, and development**. This summary highlights some of the key things we learned.

EDUCATION

9 in 10 children stopped attending school in person during the first lockdown, and **less than half** attended during the second lockdown.

51%
in remote education saw **no progress**

Only half of the children that stayed home from school **continued their education online**, mostly parent-led. Parents of children in remote education felt that their children had **missed out** on key learning activities and half reported that their child hadn't **progressed academically.**

DAILY LIFE

Lockdowns disrupted children's sleep and levels of physical activity. Parents were worried about how this affected their **children's weight, mood and motor development.** However, these changes had been **positive** for some, or disruptive in **different** ways (e.g., more sleep or less sleep). Parents felt that these had made worse by the lack of access to group and school activities.

58%
were less physically active during lockdowns

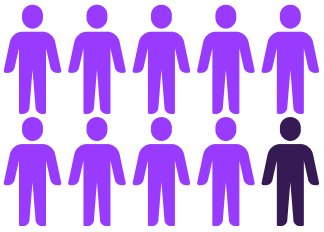
Laura Nixon; Gema Milla de la Fuente; Vassilis Sideropoulos; & Monica Lakhanpaul (on behalf of the research team)

PHYSICAL HEALTH & CARE

9 out of 10 children had experienced **delays or cancellations** of medical appointments.

Routine clinical appointments were the most affected, few children were able to access **in-person care**, and only **10%** of scheduled surgeries went ahead as planned.

9 in 10 children



experienced delays or cancellations

MENTAL HEALTH & BEHAVIOUR

69%
had worse emotional wellbeing

Over two thirds of parents reported that lockdowns had a negative impact on their child's **emotional wellbeing**, and **ten times as many** children were often or almost always **unhappy** during lockdowns.

Parents also reported that children were considerably more defiant, aggressive, impulsive, reactive to stressors and presented with an increase in tantrums and 'unusual' behaviours such as head banging.

DEVELOPMENT & SUPPORT

Many children could not access their regular developmental support appointments. Access to occupational health, physiotherapy and Early Years support appointments were most impacted, with only around half continuing during the pandemic.

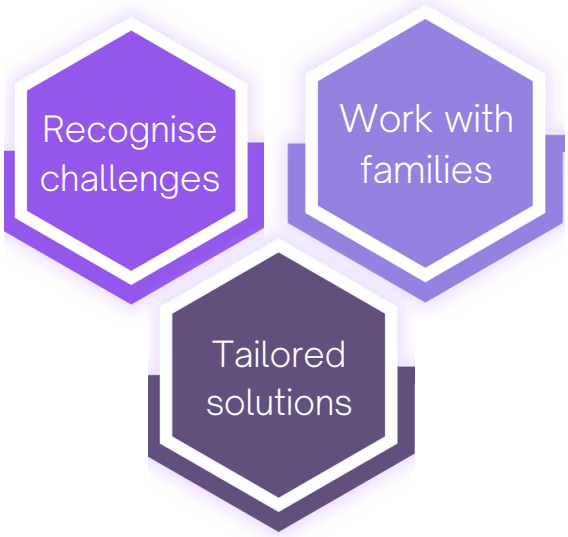
Parents felt these delays had **significantly impacted** their children's **physical, social, speech and cognitive development**, and were concerned about the **long-term impact** this could have on their child's future progress.

60%
reported decreased **social skills**

Laura Nixon; Gema Milla de la Fuente; Vassilis Sideropoulos; & Monica Lakhanpaul (on behalf of the research team)

RECOMMENDATIONS

Children with Down syndrome faced **significant disruption** during the pandemic which could have **long-term 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 Down syndrome 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.

MORE INFORMATION

This research summary summarised statistics from a larger report about experiences during and immediately after the lockdowns. The **longer-term concerns** based on the stories parents shared in the survey's written responses are reported in the British Journal of Special Education (Nixon, 2025). For more information, contact **Prof. Monica Lakhanpaul** at m.lakhanpaul@ucl.ac.uk.

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