



AIMS

This study aimed to explore the experiences of parents of children with an Intellectual and Developmental Disability (IDD) and a rare genetic disorder during the COVID-19 pandemic.

WHAT DID WE DO?

We spoke to 23 mothers during the first UK national lockdown as a result of the COVID-19 pandemic (July 2020). Parents completed an online survey followed by an interview over the phone, which was then analysed to identify key themes.

COVID IMPACT



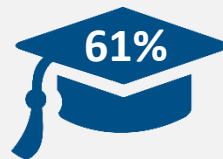
of families were shielding



87% reported that restrictions on leaving home had been stressful for their child



reported the family had difficulty following the government recommendations



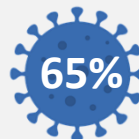
reported that their child's school had been closed

PARENT MENTAL HEALTH

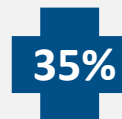


A quarter of parents reported anxiety symptoms

CHILD WORRIES



of children were reported to be worried about getting infected with COVID-19



were concerned about their physical health

UNEXPECTED POSITIVES

74% families reported at least one positive change as a result of the pandemic



INTERVIEWS: WHAT PEOPLE SAID

SOCIAL DISTANCING IS THE NORM

"We've been in lock down since he was born"

**FEWER RESOURCES,
BUT BEHAVIOURAL ISSUES ARE
THE SAME**

EXPLAINING COVID CHANGING
"How do you explain a pandemic?"

**MANAGING
PRE-EXISTING
CHALLENGES**

PLANNING FOR COMPLEX NEEDS

"there's a lot more things that I needed to do than the average sort of family"

TRANSITION TO TELEHEALTH

"I don't think you can replace face to face with a telephone"

HAPPY AT HOME

"Everyone's keeping distance from me and that's how I like it"

SPENDING TIME TOGETHER AND SLOWING DOWN

"It brought us a lot closer together"

MIXED EMOTIONS

DESPERATE FOR HUGS

"I don't like lockdown because I want snuggles with my nanny"

LEFT BEHIND

"I feel like they just left people who are vulnerable behind for two months."

STRAINED RELATIONSHIPS

"Being constantly 24/7 together definitely did build up pressure"

ADAPTATIONS AREN'T ALWAYS APPROPRIATE

"That is very difficult to do when you have special needs"

SUPPORT MATTERS

CHECKING IN

"just being able to have that support bubble, rather than being locked in your own four walls"

1:1 SCHOOLING IS BEST

"I can't get [child] to pick up a pencil without some encouragement"

ACCESS TO TECHNOLOGY

"I think the first thing to do is make sure everyone is able to access what they're providing"

SCHOOL IS RESPITE FOR EVERYONE

iMAGINE id

KEY FINDINGS



EMPOWER PARENTS AS EXPERTS

Adapting existing coping strategies: Families were able to draw on their previous experience and coping strategies and were able to adapt these to the pandemic.

Guidance, with autonomy: Parents are experts on their child's needs. With support, parents were able to integrate specialist care from multiple sources.



PROMOTE TAILORED DIGITAL INTERVENTION

Hardware is a starting point, not a solution: Access to technology is a starting point but these services need to be adapted to be inclusive, otherwise they may increase inequalities. Services need to approach parents directly to identify how support would be most appreciated.

Tele-medicine as complementary care delivery: Some families enjoyed the flexibility of tele-medicine, but it was not an appropriate substitute for in-person assessments. Parents felt it hard to communicate the complex needs of their child over the phone. Blended care will likely be the most appropriate approach.



SUPPORT PARENT MENTAL HEALTH TO SUPPORT THE CHILD

Fostering a sense of community: The parents we interviewed displayed great resilience, but this came as a detriment to their own mental health and wellbeing. Many described high levels of distress and being close to burn-out, unable to access respite care or specialised support.

Short but regular check-ins: Regular check-ins with services and schools were perceived as helpful and supportive.

School as respite: Schools provide respite and specialist education for IDD families. The re-opening of special schools and special educational need units within mainstream schools could help mitigate some of the negative mental health impacts on parents and IDD children.

Our findings demonstrate the impact of COVID-19 on families caring for children with IDD. We are conducting a follow-up study to understand the long term consequences of COVID-19 on families taking part in this research.