

Report 01: Daily life



The CoIN Study aims to track the wellbeing of families of children with rare neurogenetic syndromes throughout the Covid-19 crisis. Recruited families are invited to complete an initial baseline survey and monthly follow-up survey, which ask about family life and relationships, access to healthcare and education, overall health and wellbeing, their child's behaviour and how they are coping during the Covid-19 pandemic.

The findings from this study will identify and characterise the specific challenges faced by families of children with rare neurogenetic disorders during the pandemic and their immediate and long-term impact on family wellbeing and mental health. The responses provided by families will be shared with charities and support organisations to identify and provide better ways of supporting families now and in the future

Focus of this report

The aim of this report is to provide descriptive data on the daily life of families in the CoIN sample during the Covid-19 pandemic. This report contains the data of 159 parents/carers who completed the baseline survey in May-October 2020. Data presented is calculated as a percentage of the total number of complete responses for each individual survey item.

Sample characteristics

- Parents/carers were aged 21-67 years old (mean age: 40.3 years)
- Most parents/carers were female (91.2%)
- The majority of parents/carers were employed, including self-employed (61.7%)
- The most common average household income was £30,000--59,999 a year (32.1%)
- Children were aged 0-15 years old (mean age: 8.2 years)
- 49.7% of children were female and 50.3% were male
- 37.6% of children attended a special education preschool/school
- Over 100 different rare disorders
- 73.0% of children live with a general learning disability, including intellectual disability and developmental delay, and 25.8% are diagnosed with autism spectrum disorder

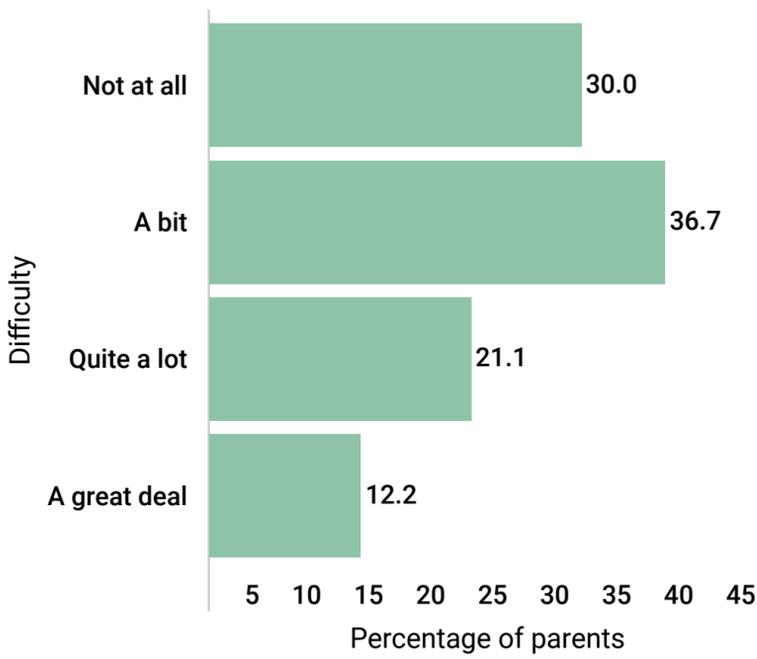
Key Findings

- Half of children were considered high risk and the majority of parents did not find it difficult to shield their child at home.
- The majority of children did not have a regular routine.
Parents who found it difficult to keep a similar routine to before the outbreak of Covid-19 and those whose child did not have a regular routine reported they had tried to, but their child was not able to stick to a similar and/or regular routine.
- Half of parents felt they were able to support their child's educational and caring needs.
- The majority of children were home-schooled or were not in childcare during lockdown.

Isolation and Shielding

Parents were asked whether their child was high risk and the difficulties of shielding their child, including gaining access to personal protective equipment (PPE). Parents were also asked about their own isolation status.

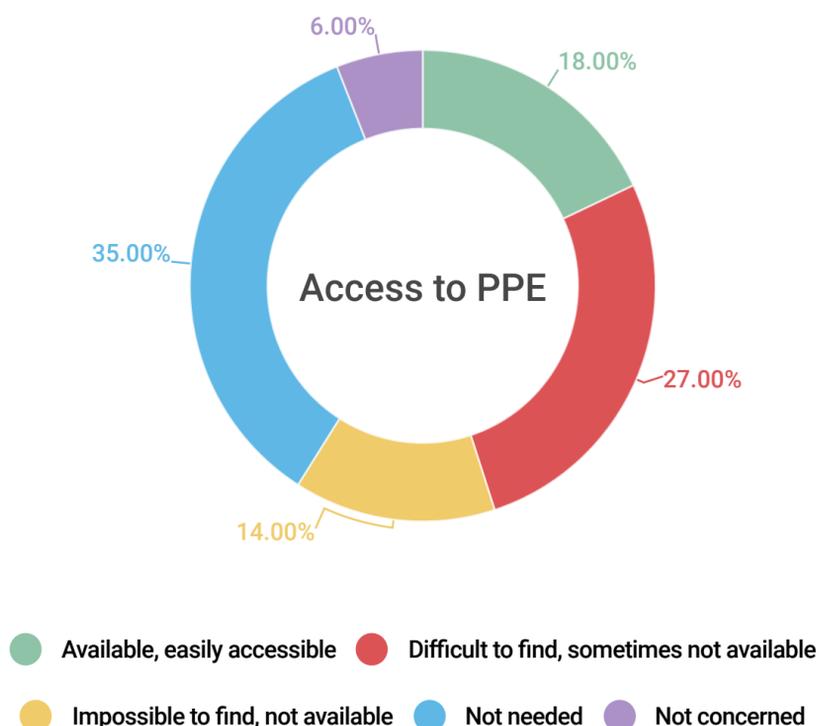
Is it difficult for parents to shield their child at home?



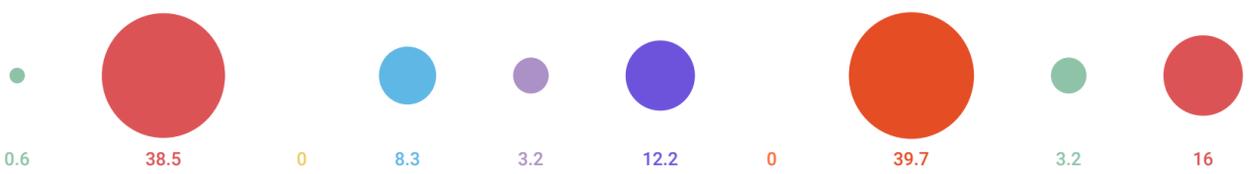
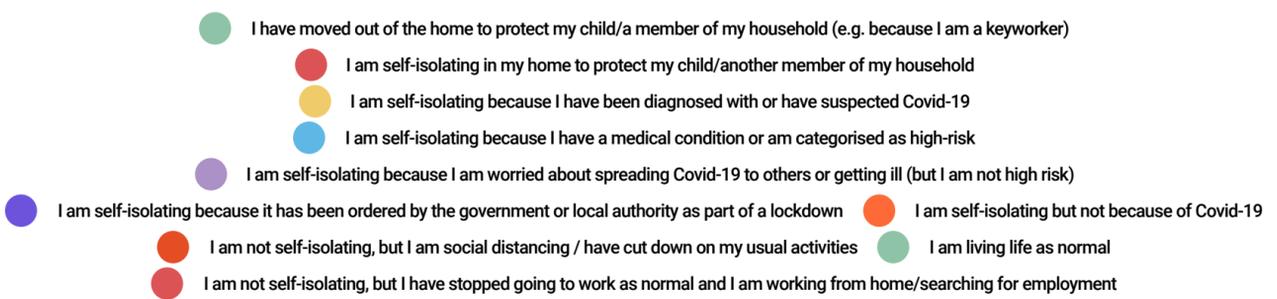
50.1%
of children were considered high risk.

66.7%
of parents did not find it difficult to shield their child at home.

18.0%
of parents found it easy to access PPE
vs.
27.0%
of parents found it difficult to access PPE



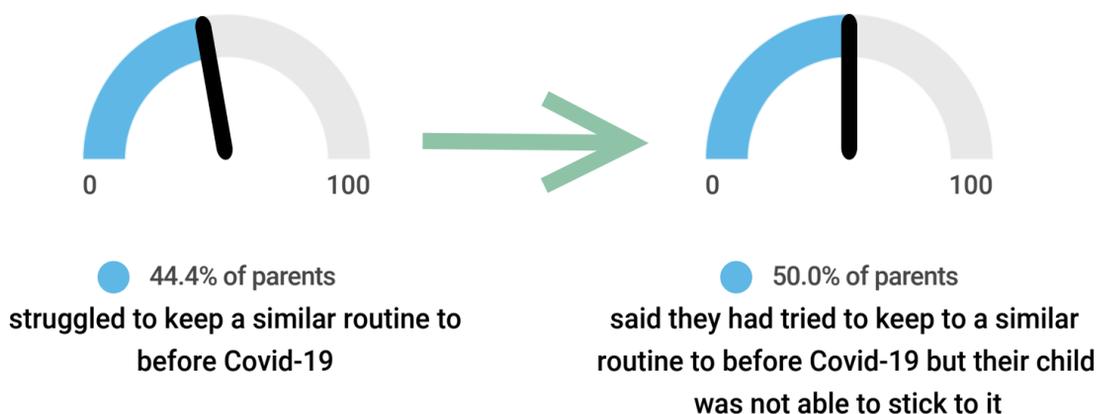
Current isolation status



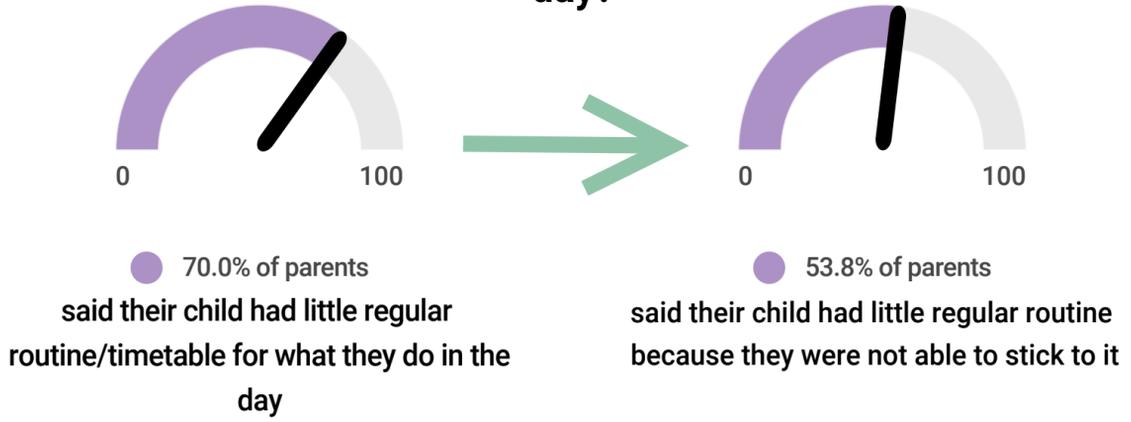
Daily routines

Parents were asked about the impact of Covid-19 on their child's daily routine. Below we present the percentage of parents who reported disruption to daily routines and the percentage of children who found it difficult to stick to daily routines.

Could you keep a similar routine to before Covid-19?



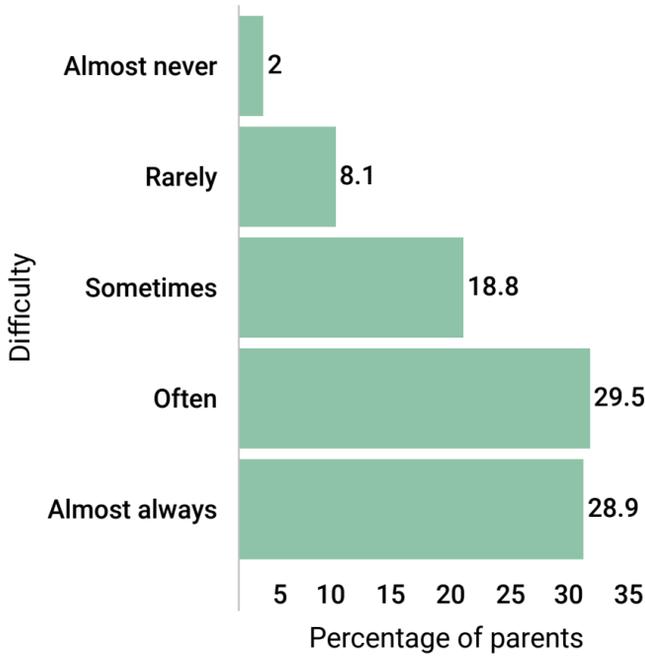
Does your child have a regular routine/timetable for what they do in a day?



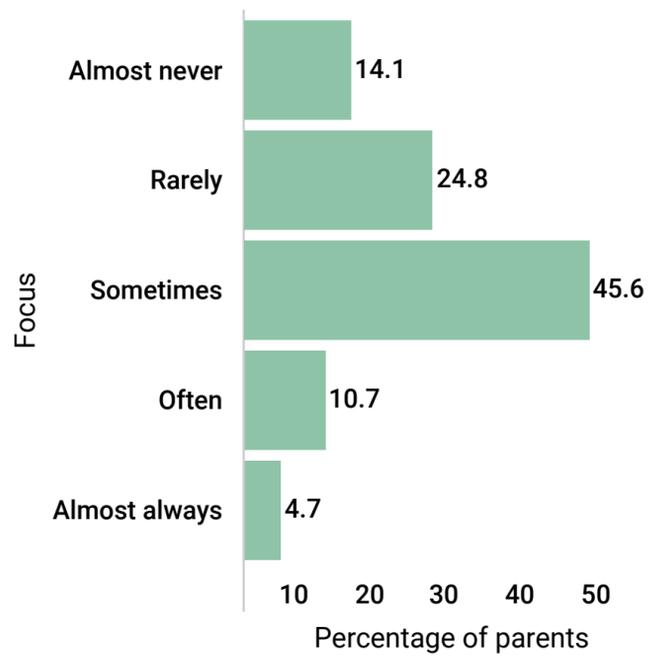
Paid and Domestic Work

Parents were also asked how looking after their child at home impacted their paid or domestic work, including how difficult they found it to do their paid or domestic work and how focused they felt in their paid or domestic work.

How difficult is it to do your paid/domestic work?



How focused did you feel in your paid/domestic work?



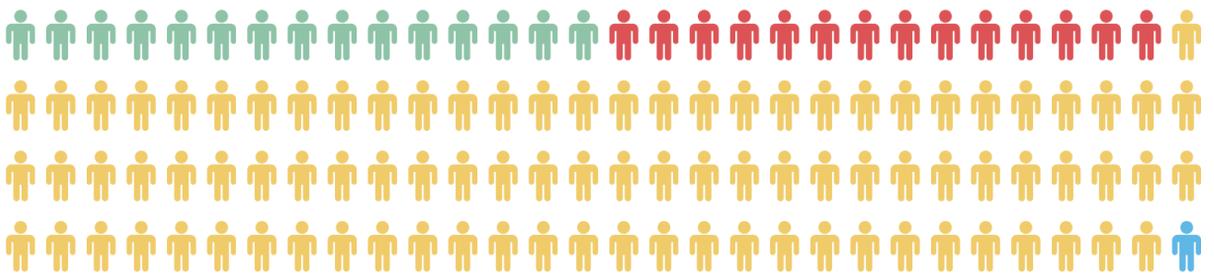
58.4%

of parents 'almost always' and 'often' found it difficult to do their paid or domestic work.

Education and Childcare

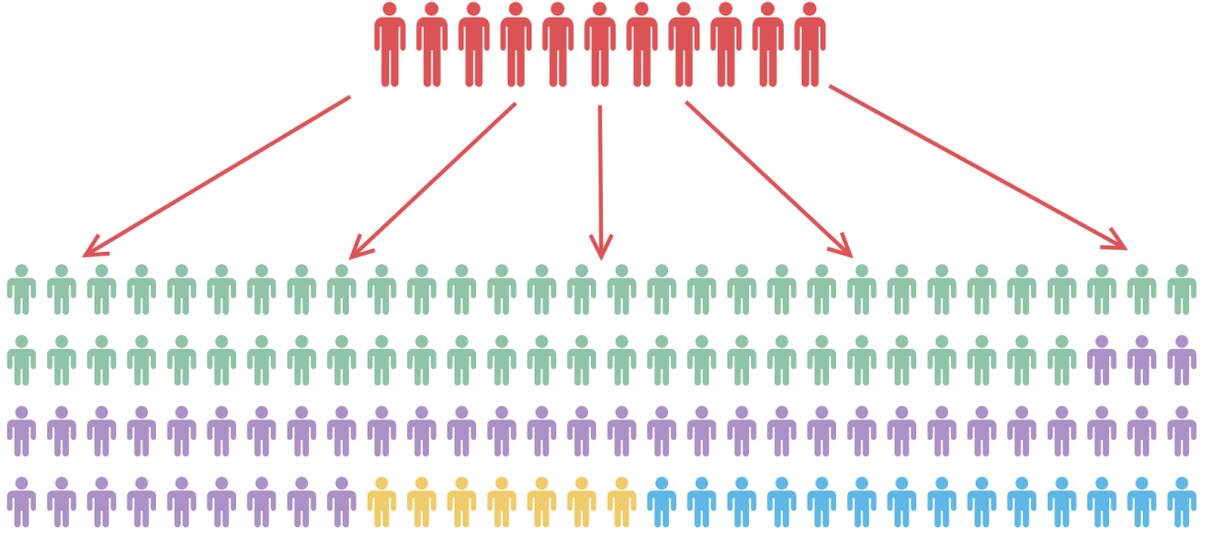
Parents were asked how their child's education or childcare arrangements were impacted by the national lockdown in the UK from March to June 2020. Below we present the percentage of children.

Were your child's education/childcare arrangements changed during lockdown?



- No change from before Covid-19
- Attends physical school/preschool/childcare at least some days
- My child has had to be homeschooled/ I don't have childcare
- My child has moved back from a residential care facility

Why did your child attend physical school/preschool/childcare?



- Child's parent/carer is considered critical to the Covid-19 response
- Child is considered vulnerable
- Child is supported by social care
- Child has safeguarding and welfare needs

Parents were also asked how able they felt to support their child's educational or caring needs:



57.1% of parents felt they were able to support their child's educational or caring needs