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.

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.

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.
- 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?

- Not at all: 30.0%
- A bit: 36.7%
- Quite a lot: 21.1%
- A great deal: 12.2%

Percentage of parents of children were considered high risk.

- 50.1% of parents found it easy to access PPE
- 18.0% of parents did not find it difficult to access PPE
- 27.0% of parents found it difficult to access PPE
- 66.7% of parents did not find it difficult to shield their child at home.
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.

58.4% of parents ‘almost always’ and ‘often’ found it difficult to do their paid or domestic work.

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?

- 44.4% of parents struggled to keep a similar routine to before Covid-19
- 50.0% of parents said they had tried to keep to a similar routine to before Covid-19 but their child was not able to stick to it

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

- 70.0% of parents said their child had little regular routine/timetable for what they do in the day
- 53.8% of parents said their child had little regular routine because they were not able to stick to it

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?

- Almost never: 2%
- Rarely: 8.1%
- Sometimes: 18.8%
- Often: 29.5%
- Almost always: 28.9%

Percentage of parents

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

- Almost never: 14.1%
- Rarely: 24.8%
- Sometimes: 45.6%
- Often: 10.7%
- Almost always: 4.7%

Percentage of parents

58.4% of parents ‘almost always’ and ‘often’ found it difficult to do their paid or domestic work.
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 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.