

# Report 05: Parental Mental Health and Wellbeing



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 parental mental health and wellbeing 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

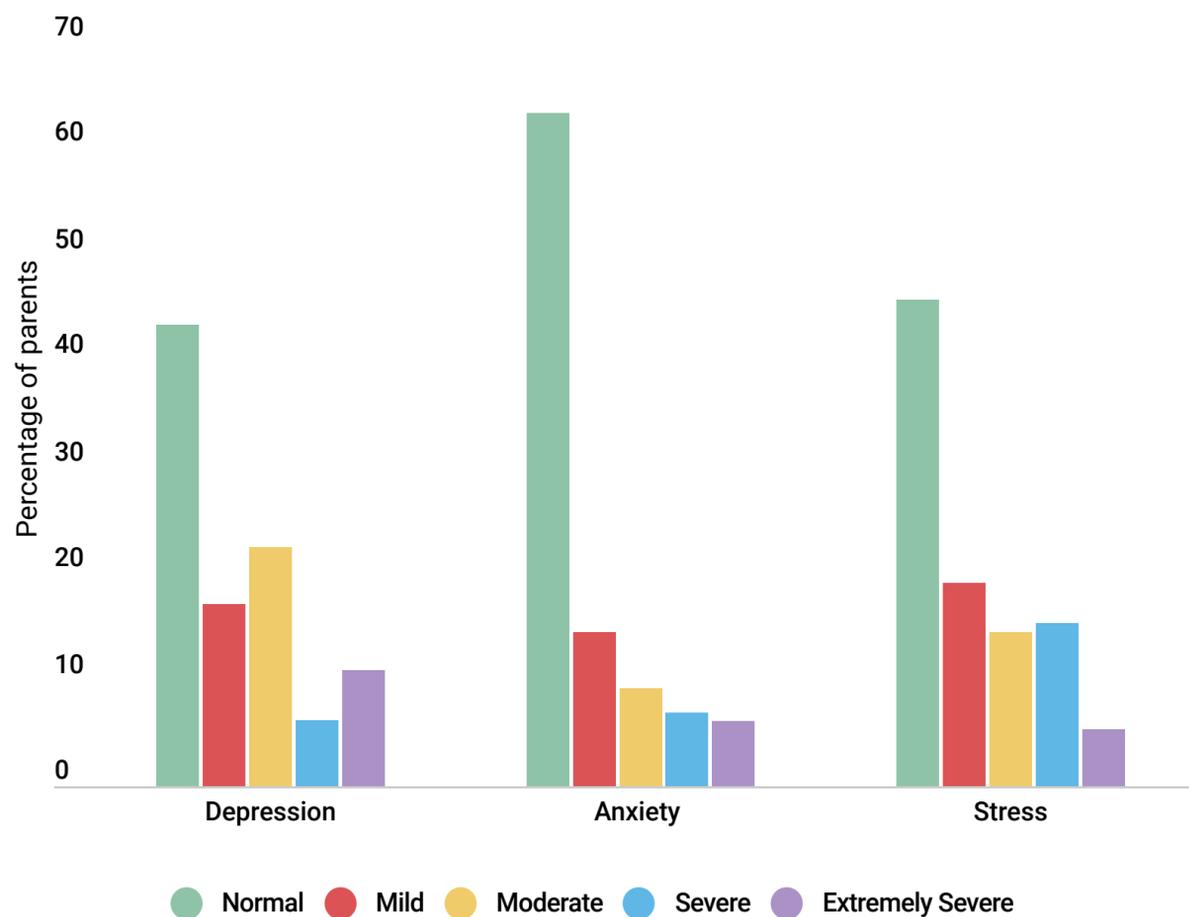
- Parents/carers were aged 21-67 years old (mean age: 40.3 years)
- Most parents/carers were female (91.2%)
- The majority of parents/carers were employed, including self-employed (61.7%)
- The most common average household income was £30,000--59,999 a year (32.1%)
- Children were aged 0-15 years old (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

- Parents in the CoIN sample experienced elevated levels of stress, anxiety and depression compared to the other parents during the Covid-19 pandemic.
- Severe stress is experienced by more parents than severe depression or anxiety.
- 60.8% of parents did not enjoy their usual activities.
- Key sources of parental stress included child's future, wellbeing, education and behaviour and own future plans.

## Depression, Anxiety and Stress during Covid-19

Parents completed a standardised assessment of depression, anxiety and stress called the Depression, Anxiety and Stress Scales, 21 items (DASS-21).

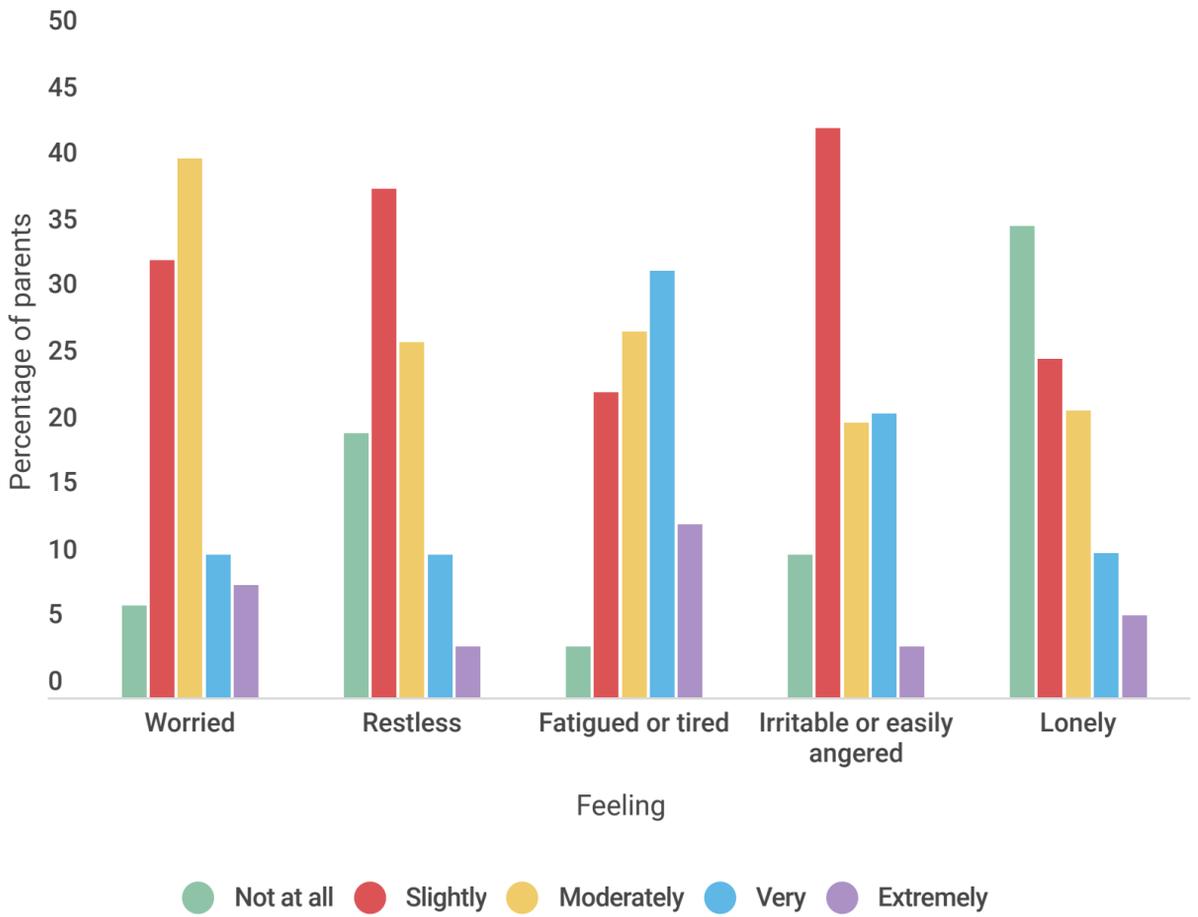


The majority of parents had scores below a moderate level (i.e., scored in the 'Normal' and 'Mild' range) on all three subscales (depression, 60.5%; anxiety, 77.9%; stress, 64.9%). For the depression subscale, 39.5% of parents had a score of moderate to extremely severe, compared to only 35.1% for the stress subscale and 22.1% for the anxiety subscale. In addition, we found a greater proportion of parents scored in the 'Severe' and 'Extremely Severe' range for stress (20.6%) than depression (17.1%) or anxiety (13.0%).

The DASS-21 has also been used by the COVID-19: Supporting Parents, Adolescents and Children during Epidemics (Co-SPACE) and COVID-19: Supporting Parents and Young Children during Epidemics (Co-SPYCE) studies. These studies have been tracking parents, young peoples, and children's mental health (children and adolescents aged 4-16 years old and preschool children aged 2-4 years old, respectively) during the Covid-19 pandemic. In their December 2020 report, Co-SPYCE report the mental health of parents who had completed the DASS-21 between 17/04/2020 and 31/05/2020. In line with our findings, they found the majority of parents had scores on all three DASS sub scales below a moderate level. They also found a greater proportion of parents scored in the 'Severe' and 'Extremely Severe' range for stress (9.1%) than depression (7.6%) or anxiety (5.0%), but the levels of parents scoring in this range is elevated in the CoIN sample during the pandemic.

# Parent Feelings

Parents were asked about how they had felt over the past two weeks.



45.4% of parents reported feeling extremely fatigued or tired (i.e. responded 'Very much' and 'Extremely').

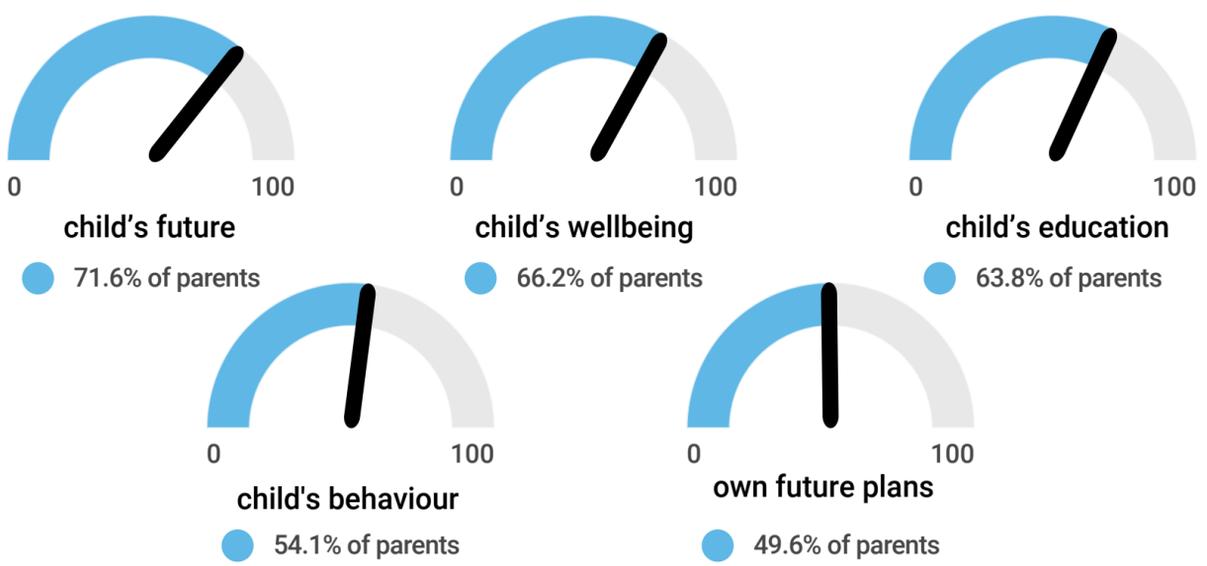


60.8% of parents reported they were unable to enjoy their usual activities over the past two weeks.

## Parent Worries

Parents were asked how stressed they had felt over the past week in response to several potential stressors. Below we report the percentage of parents who indicated a stressor has caused them significant stress.

### Top 5 Sources of Parent Stress



In their January 2021 report, Co-SPACE report the percentage of parents who had indicated a child-related stressor had caused them significant stress. Between May-October 2020 43.8% of parents reported being significantly stressed about their child's wellbeing, 39.2% by their child's screen time, 38.9% by their child's education, 36.0% by their child's future and 28.7% by their child's behaviour. The percentage of parents experiencing significant stress in relation to a child-related stressor are elevated in the COIN sample during the pandemic.

### Covid-19 specific Sources of Parent Stress

