

Report 02: Coping, Support and Resources



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 coping, access to resources and support 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

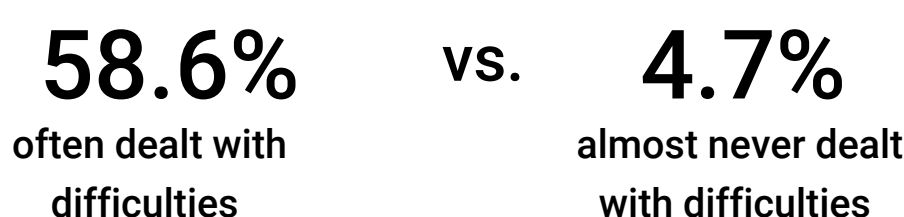
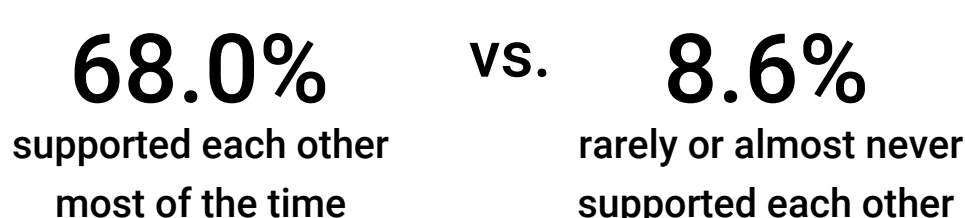
- Parents/carers were aged 21-67 years old (mean age: 40.3 years)
- Most parents/carers were female (91.2%)
- The majority of parents/carers were employed, including self-employed (61.7%)
- The most common average household income was £30,000--59,999 a year (32.1%)
- Children were aged 0-15 years old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

- The majority of families supported each other, and most families were able to deal with difficulties during the pandemic.
- Key areas parents would like support with include managing their child's education, behaviour and emotions, caring for their child and accessing healthcare.
- Parents would prefer to receive support via online written material, online parent support groups and webinars/podcasts

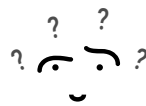
Coping and Support

Parents were asked the extent their family supported each other and dealt with difficulties relating to the crisis. They were also asked to rate the quality of support they received from extended family and friends.



15.1%

felt negative about support from extended family and friends



44.7%

felt mixed about support from extended family and friends



41.3%

felt positive about support from extended family and friends

Resources

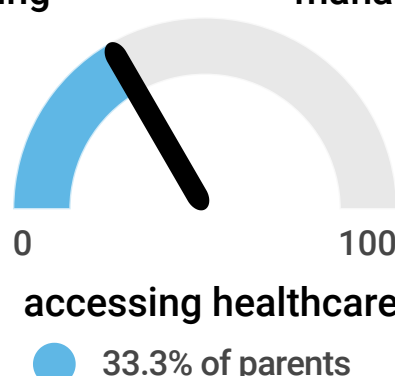
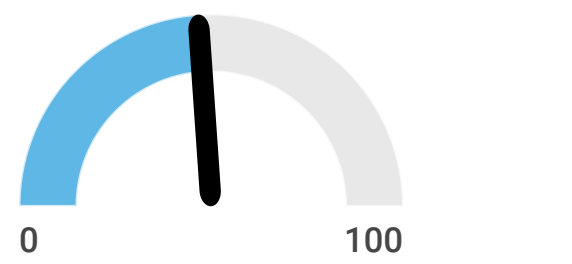
Parents were asked whether they would benefit from support, what areas they would like support in and the format they would like to receive support.



73.0%

of parents indicated they would benefit from resources relating to their child's response to Covid-19 and/or isolation

Resource areas



Resource formats

