

Report 04: Child behaviour



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 child behaviour 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

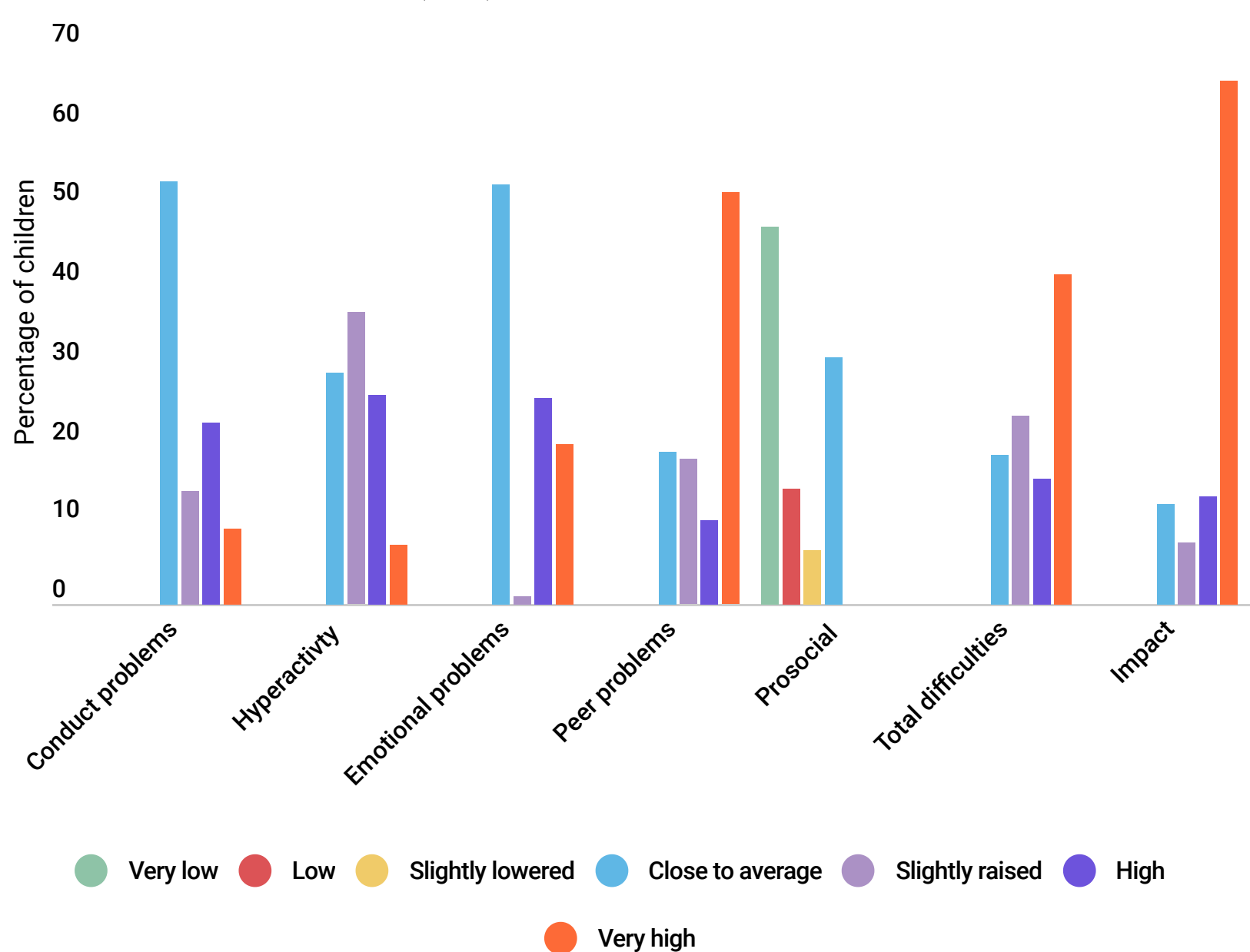
- Parents/carers were aged 21-67 years old (mean age: 40.3 years)
- Most parents/carers were female (91.2%)
- The majority of parents/carers were employed, including self-employed (61.7%)
- The most common average household income was £30,000--59,999 a year (32.1%)
- Children were aged 0-15 years old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

- Child behaviour had a significant impact on the child and the family.
- Across a range of child behaviours, for most children there was no improvement.

Strengths and Difficulties

Parents completed a standardised assessment of child behaviour called the Strengths and Difficulties Questionnaire (SDQ).



Note: The Prosocial subscale is reverse scored, such that it is scored from 'Close to average', 'Slightly lowered', 'Low', to 'Very low', whereas the other subscales are scored from 'Close to average', 'Slightly raised', 'High', and 'Very high'. 'Very low' reflects more difficulties on the Prosocial subscale, whereas 'Very high' reflects more difficulties on the other subscales.

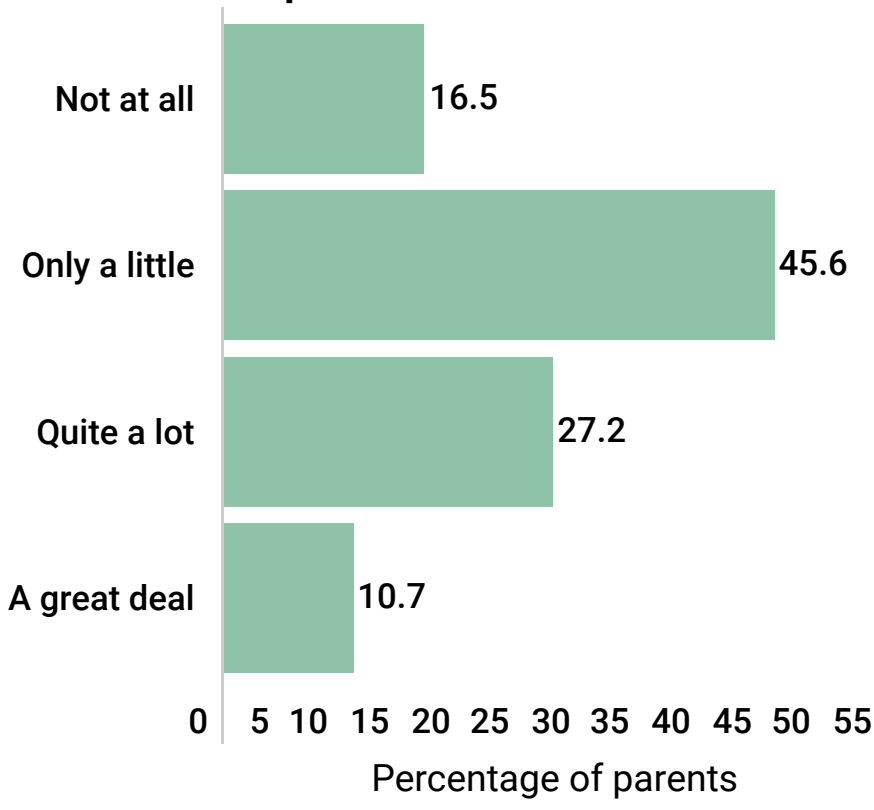
The majority of children did not experience significant difficulties (i.e., scored 'Close to average' and 'Slightly raised') in comparison to the percentage of children who experienced significant difficulties (i.e., scored 'High', and 'Very high') on the Conduct problems (67.6% vs. 32.4%), Hyperactivity (66.0% vs. 34.0%) and Emotional problems (53.9% vs. 46.2%) subscales. In contrast, the majority of children did experience significant difficulties (i.e., scored 'High' and 'Very high'/'Low' and 'Very low') versus the number of children who did not experience significant difficulties (i.e., scored 'Close to average' and 'Slightly raised'/'Slightly lowered') on the Peer problems (62.5% vs. 37.5%) and Prosocial (62.1% vs. 37.9%) subscales. In total, a greater percentage of children (57.4%) experienced significant difficulties (i.e., scored 'High' and 'Very high' on the Total difficulties score) compared to those that did not (42.6%; i.e., scored 'Low' and 'Very low'). Additionally, the impact of these difficulties were 'Very high' in 66.0% of children, such that it would cause significant stress or impairment.

Recently the SDQ was used by the Office for National Statistics (ONS) to generate the Mental Health of Children and Young People (MHCYP) in England 2020 report. When examining average scores of children aged 5-16 years old during the pandemic (surveyed in July 2020), they found the average score on all of the SDQ subscales fell in the 'Close to average' range, as well as the Total difficulties and Impact scores. This differs to children in the CoIN sample, who during the pandemic experience elevated difficulties in peer interactions and executing prosocial behaviours as well as total difficulties. Their difficulties also have a significant impact on their ability to function.

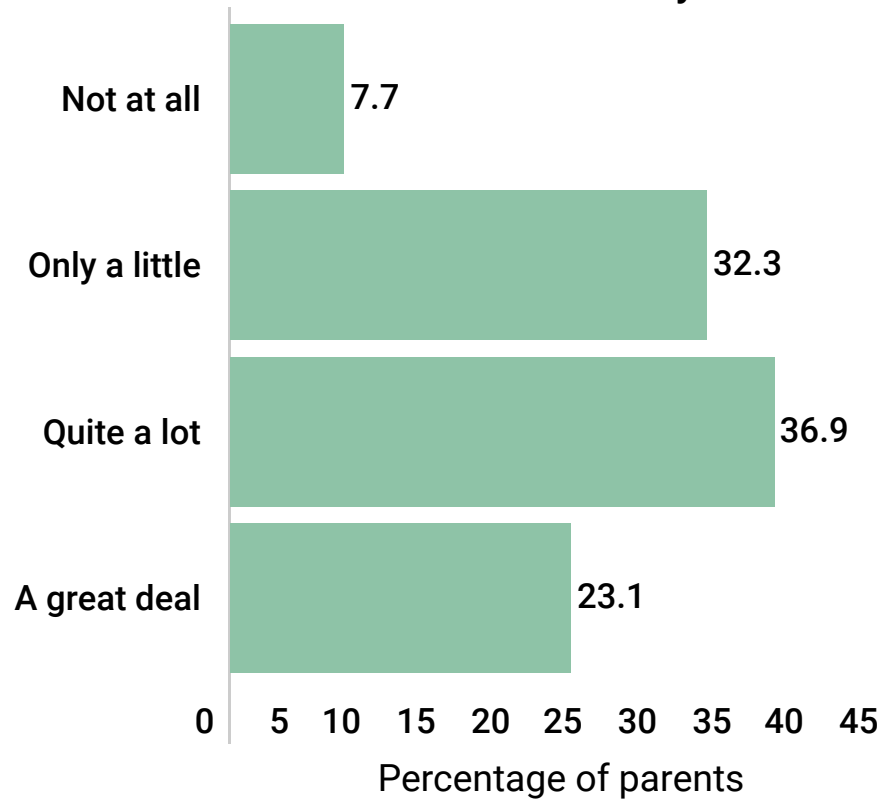
Impact of Difficulties

In addition to assessing difficulties, the SDQ also assess the impact of a child's difficulties, including how much upset/distress they cause the child and the burden they have on the family.

How much do your child's difficulties upset/distress them?



How much do your child's difficulties have a burden on the family?



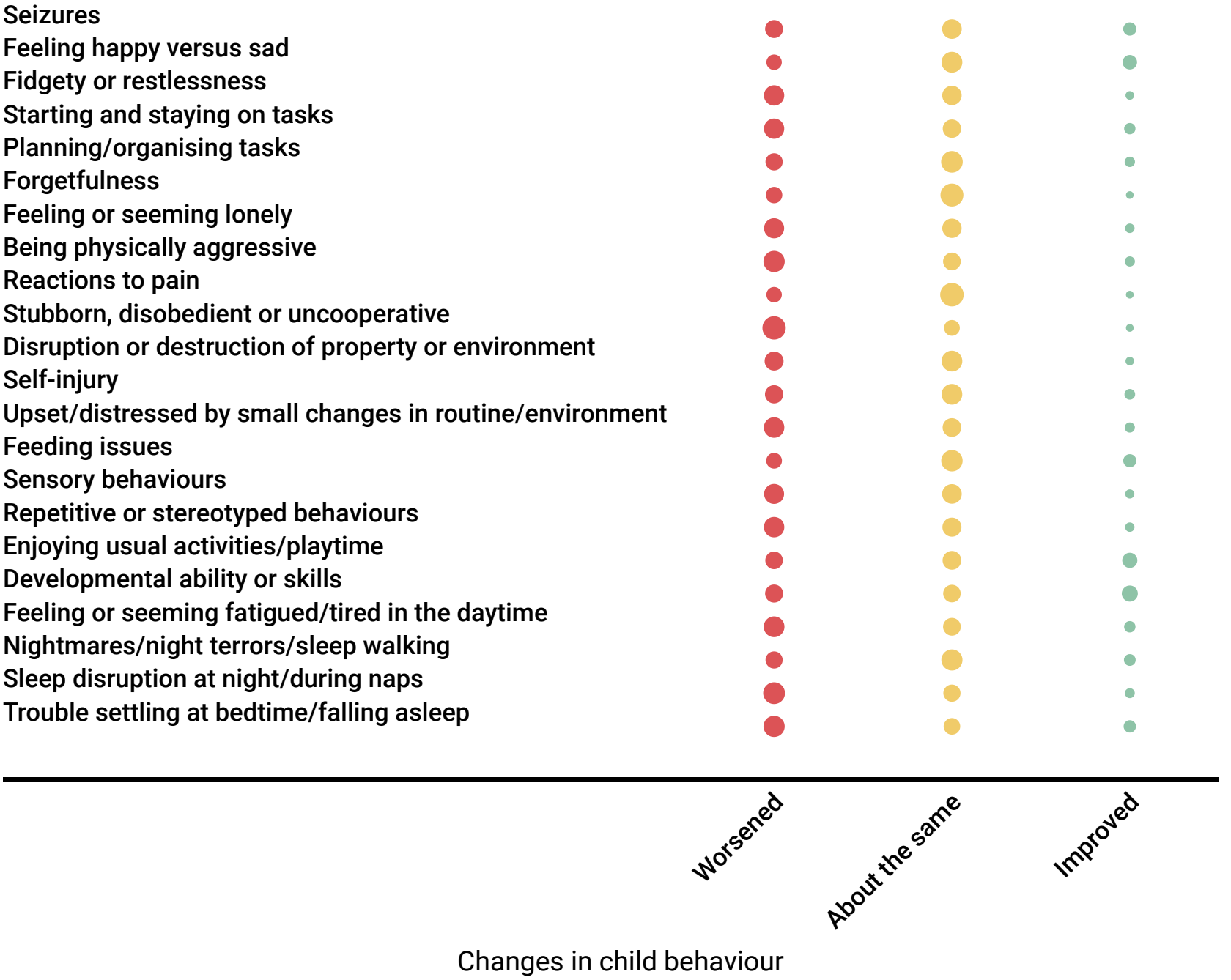
37.9% of parents report their child's difficulties cause them significant upset/distress (i.e. responded 'Quite a lot' and 'A great deal').



60.0% of families report a significant burden on child difficulties on the family (i.e. responded 'Quite a lot' and 'A great deal').

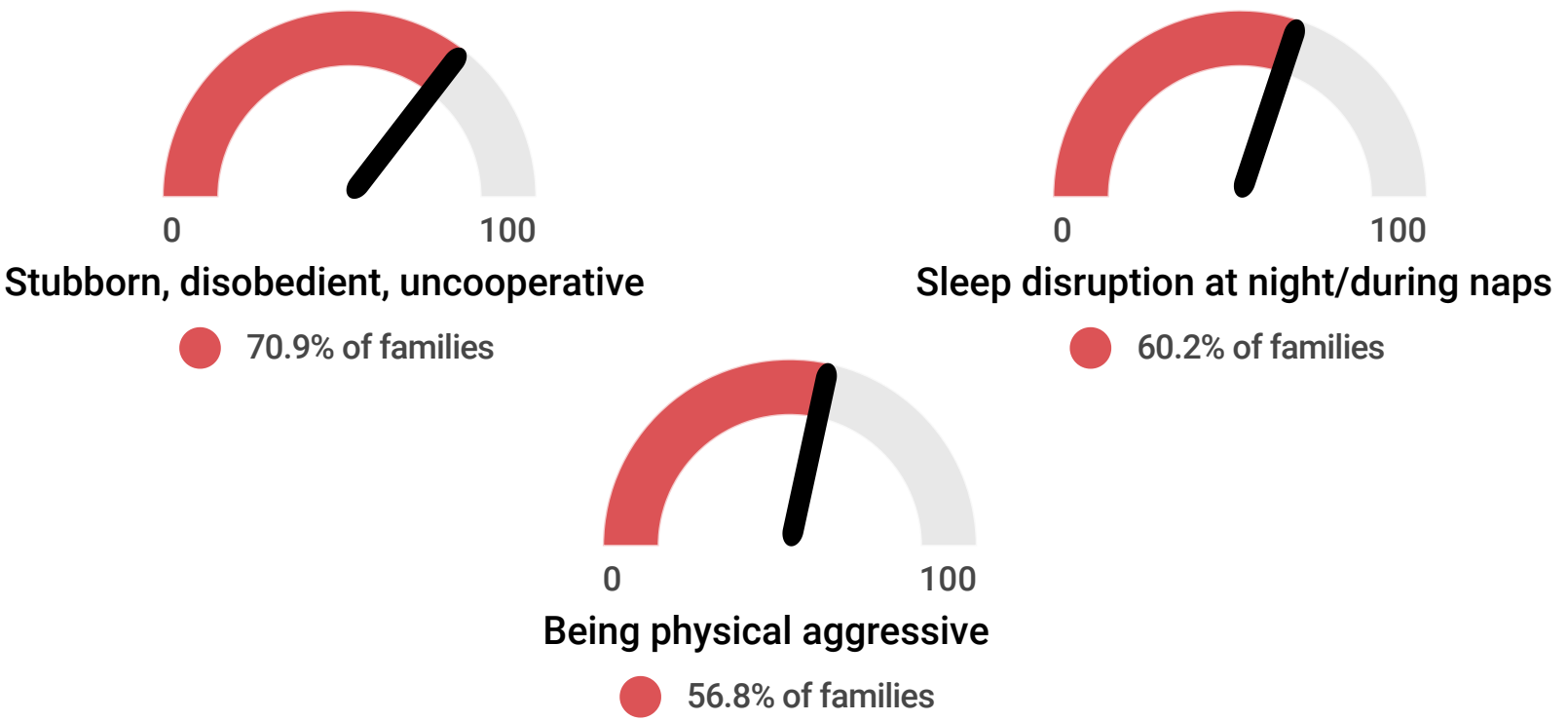
Changes in behaviour

Parents were asked to rate changes in their child's behaviour over the past two weeks. Below we report the percentage of children for which each behaviour worsened, stayed about the same, or improved.



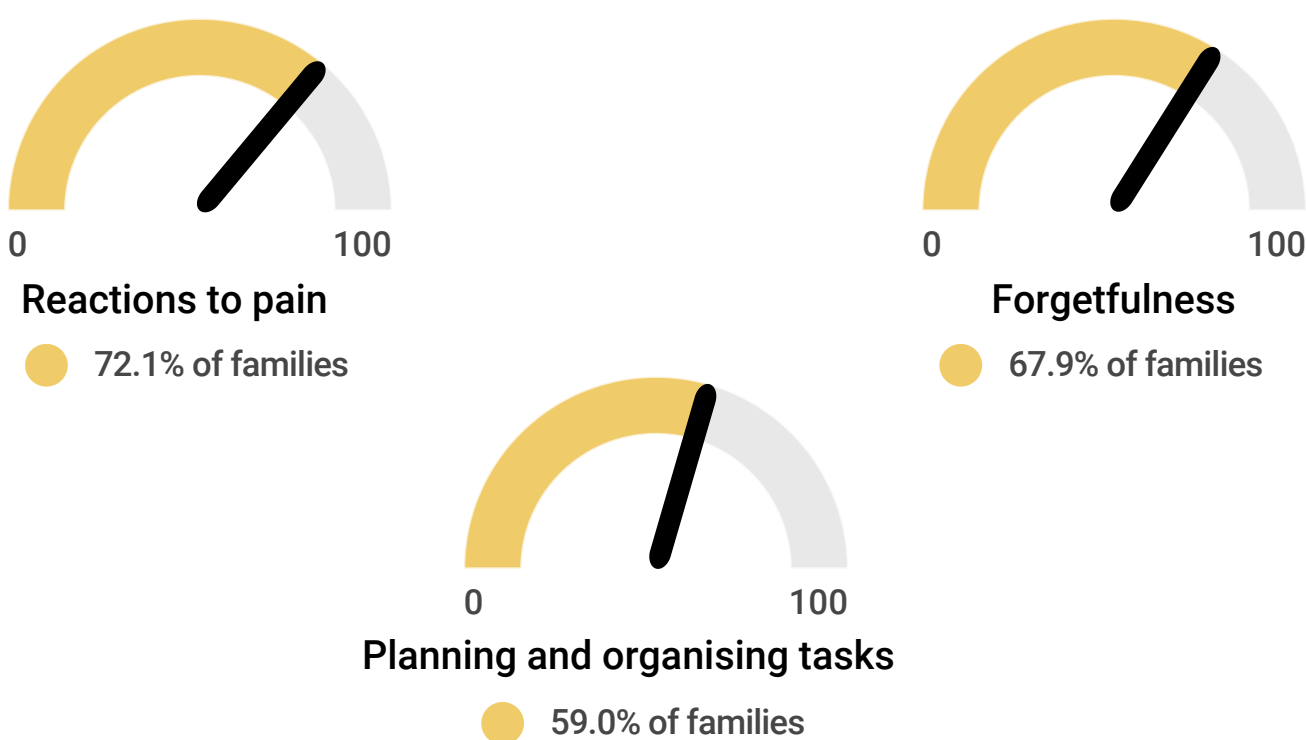
Top 3 behaviours that worsened

Below we report the top three behaviours that were rated for the majority of children as having worsened, as opposed to remaining about the same or improving.



Top 3 behaviours that stayed the same

Below we report the top three behaviours that were rated for the majority of children as having remained about the same, as opposed to worsening or improving.



All child behaviours had, for the majority of children, worsened or remained about the same compared to showing improvement.