

Report 03: Healthcare and



Interventions

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 healthcare 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

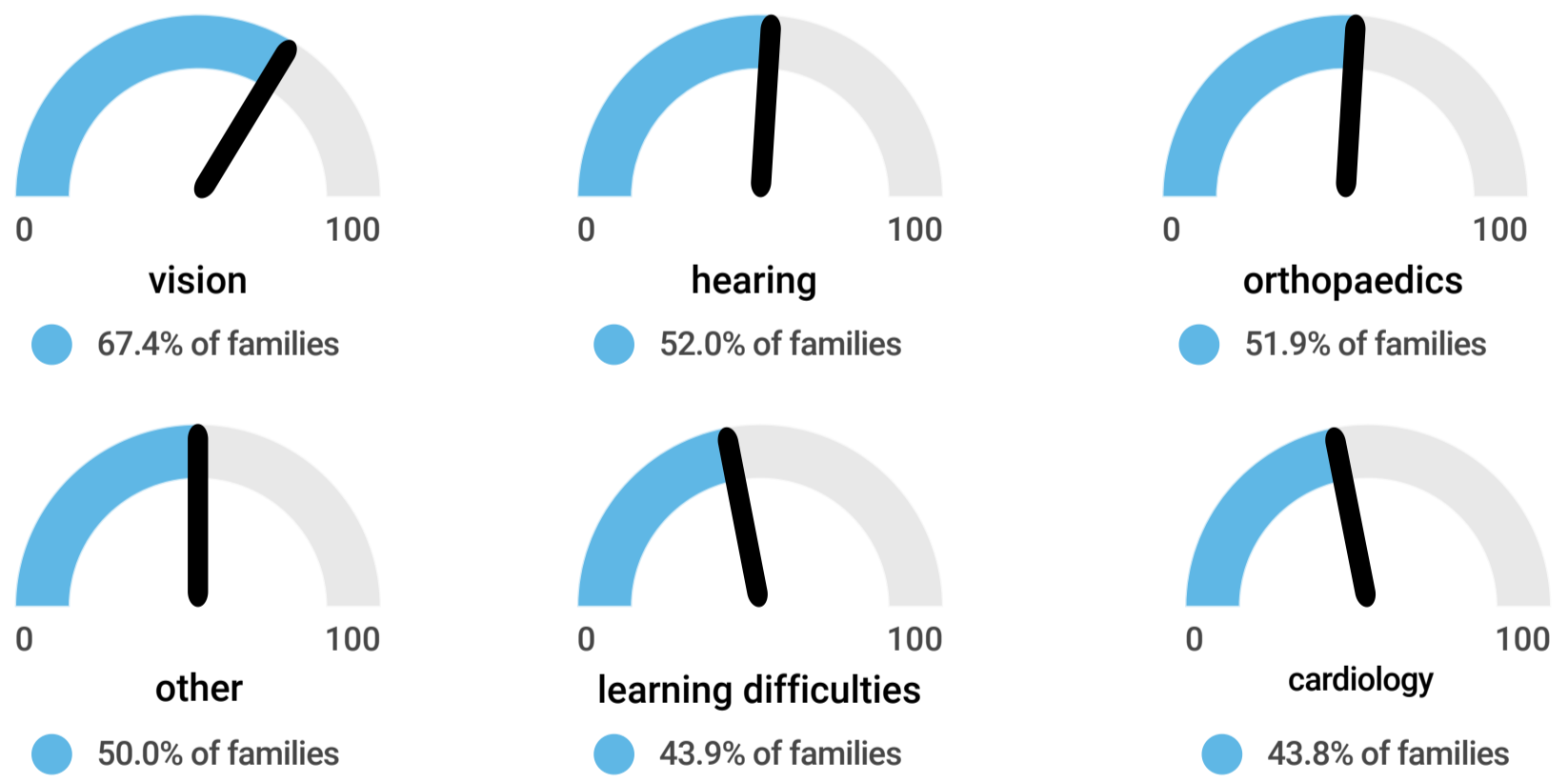
Key Findings

- For families who required access to healthcare and intervention services, vision and ABA therapy were the poorest accessed services, respectively.
- Most parents who had access to healthcare services accessed them via the phone.
- More parents found changes to the delivery of healthcare and intervention services were effective compared to ineffective.
- The majority of parents report changes to the delivery of healthcare and intervention services did not affect their child's health.

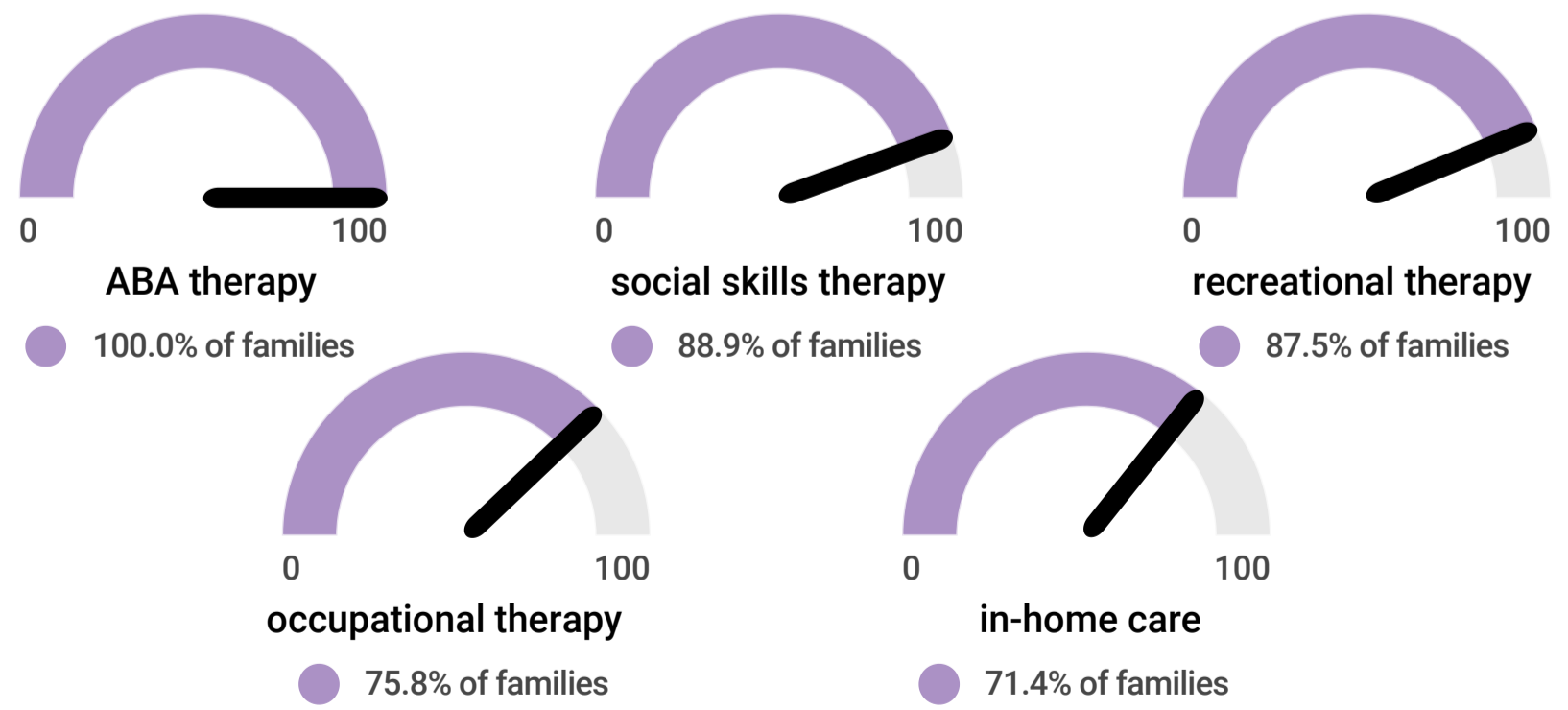
Access to healthcare and intervention services

Below we report the percentage of families who required access to healthcare and intervention services but could not access them.

Poorest accessed healthcare services

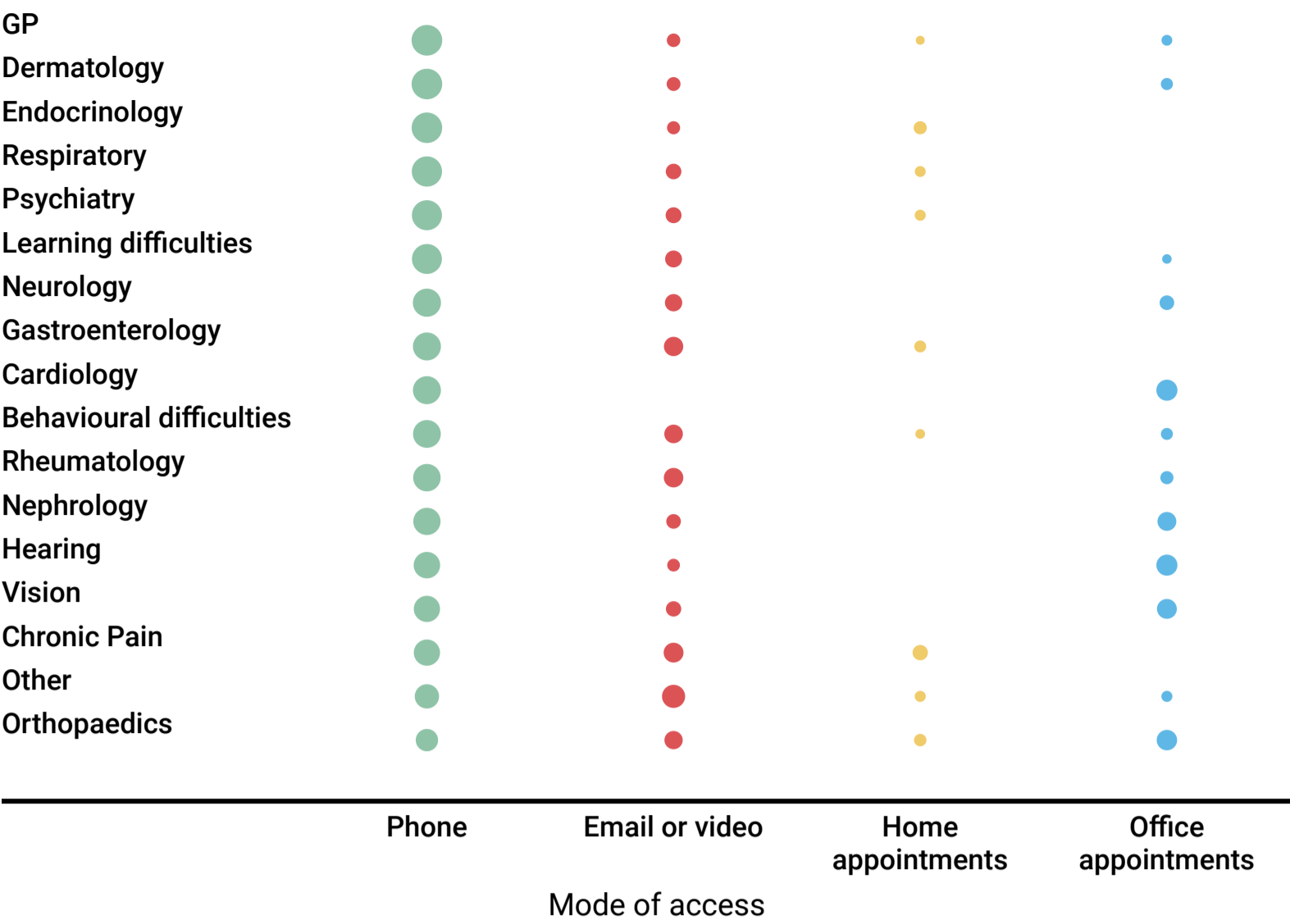


Poorest accessed intervention services



Changes to the delivery of healthcare and intervention services

Below we report the percentage of families who had access to healthcare services and their mode of access.



Parents were asked how effective they thought changes in the delivery of healthcare and intervention services were and whether these changes had significantly impacted on their child's health or medical condition.



of parents thought changes in the delivery of healthcare and/or intervention services were effective.



of parents did not find changes in access of healthcare and/or intervention services significantly impacted on their child's health or medical condition.