

Survey 2: Impact of COVID-19 on medical supports and caregiver mental health



Sent to **1,497 families**

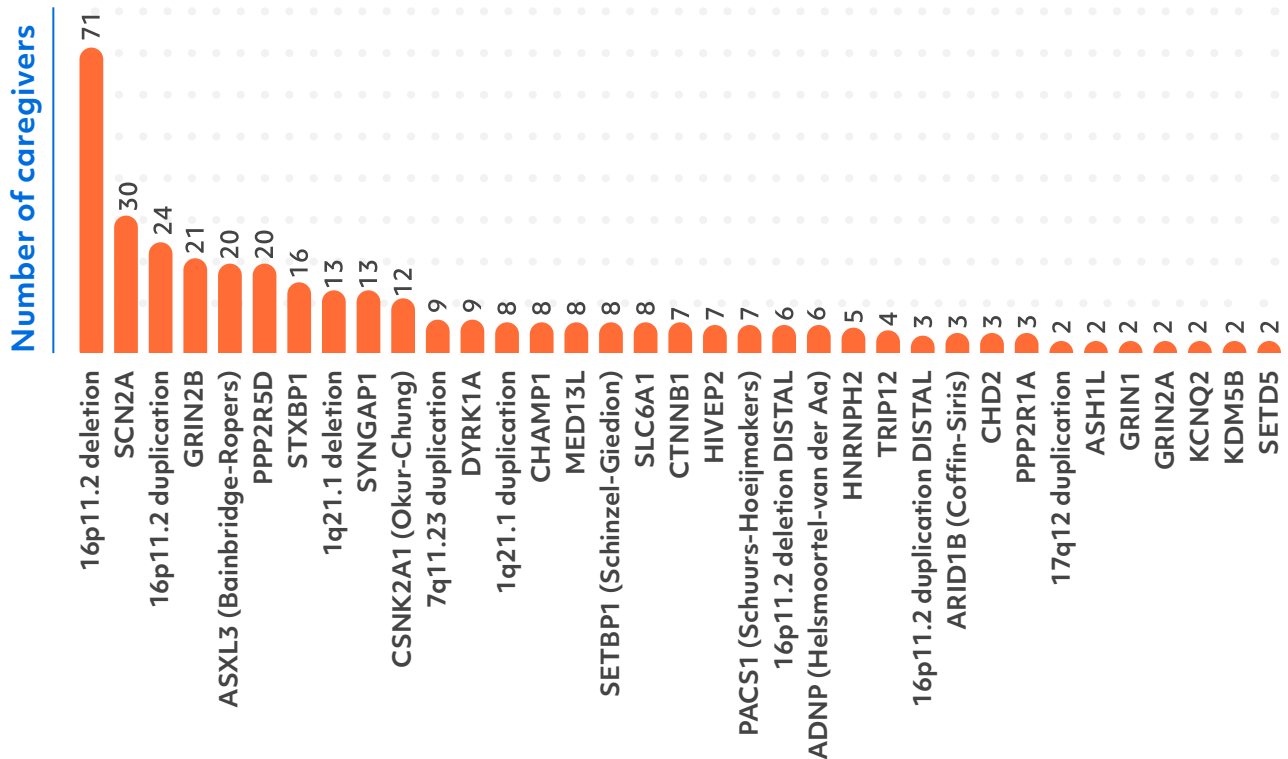
Completed by **391 families**

Representing information collected **April 29, 2020 to May 13, 2020**

Across **60 different genetic groups** and **28 countries**

Who participated?

Participants by Gene Group



One participant from each of the following genes

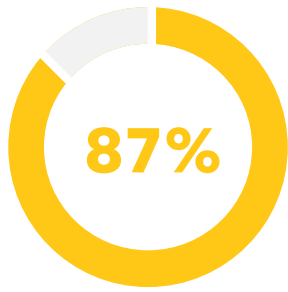


15q11.2 BP1-BP2 deletion
3q29 deletion
ANKRD11 (KBG)
AUTS2
BCL11A
CASZ1
CHD3
CHD8
CTBP1

DNMT3A (Tatton-Brown-Rahman)
FOXP1
GIGYF1
HNRNPU
KMT2E (O'Donnell-Luria-Rodan)
MBD5
NLGN4x
NRXN1

POGZ (White-Sutton)
PPP2R5C
PTCHD1
PURA
SHANK3
TAOK1
USP9X
VPS13B (Cohen Syndrome)

Effects on services



of families have had **moderate to severe disruptions** in services for their children



of families are receiving **online or remote delivery** of services, an increase since the first survey.

Percent of services that are being offered to caregivers online



Speech and language therapy **75%**

Special education services **67%**

Recreational services **21%**

PT/OT **64%**

Mental health services **85%**

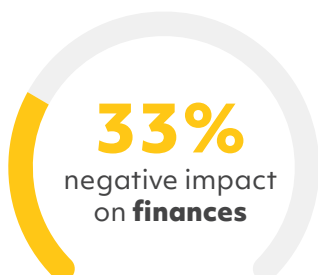
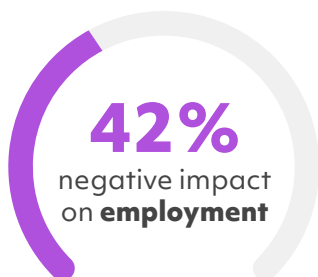
Early intervention **61%**

Adult disability services **32%**

ABA/behavioral therapy **47%**

Employment impact

Caregivers reported some impacts on employment but **most did not report a negative impact on finances** due to COVID-19.



Improved caregiver mental and emotional health

61%

of caregivers describe their overall mental health as **good to excellent**



77%

Percent of families feel moderately to extremely stressed about the disruption of services for their child

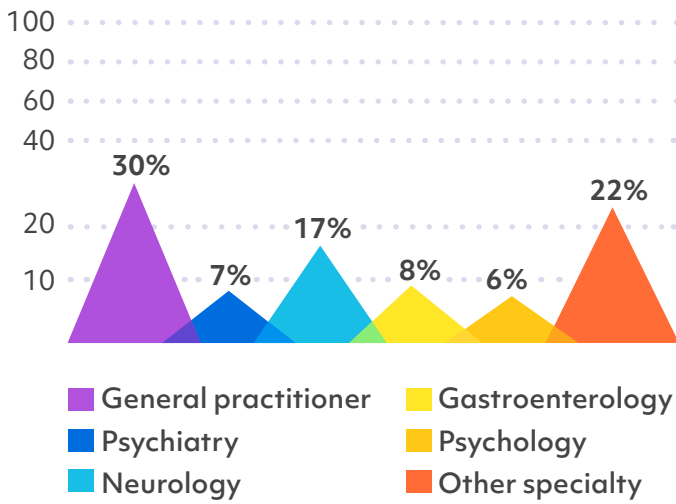
54%

Percent of families report feeling hopeful moderately to most of the time

On average, **caregivers reported a decrease** in feeling nervous, anxious, or on edge as compared to our first survey.

Medical provider info

During COVID-19 some dependents required access to physicians and other medical providers.



A majority, up to 90%, said they accessed these providers through telehealth/telemedicine, but some received services at home, in clinic or could not access these medical services.

Child behaviors

Since COVID-19, some caregivers saw an increase in behavior issues for the following:

- Repetitive behaviors **36%**
- Aggression **28%**
- Self-injury **13%**
- Anxiety **40%**
- Sleep disruption **42%**
- Refusal to participate in daily activities **41%**

Use of emergency room services

54 caregivers considered taking their child to the emergency room, and they decided:



Did not go to the ER because of fear of COVID-19 **39%**

Used telehealth instead **20%**

Went to ER did not delay **20%**

Went after a delay **13%**

Called a doctor **46%**

Medical experience and medications

Few caregivers has trouble accessing medications.



Routine appointments cancelled/postponed

65%

Scheduled procedures cancelled/postponed

34%

Trouble accessing medications **10%**



A special thank you to the families who shared their experiences

