

Impact of COVID-19 on Therapies, Services and Medical Supports



Sent to **1,496 families**

Completed by **489 families**

Representing information collected **April 1 - 7, 2020**

Across **59 different genetic groups** and **26 countries**

Who participated?



● Participating countries
86% came from North America, and the UK



Parents and Guardians

90% Female

42 years old on average

Their Children/Dependents

55% Male

10 years old on average

(ranging from < 1 year to 45 years)

Dependents with a
genetic change



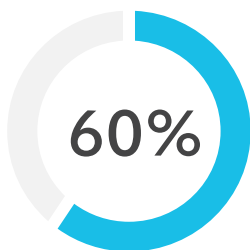
Children/Dependents have these diagnoses:

■ 27% ASD

■ 25% Seizures

■ 85% Developmental delay

Disruptions in services and therapies



of families report severe
disruptions in services, therapies
and medical supports.



77%

of families report that speech
therapy is most disrupted.

Percent of families reporting disruptions to
services, therapies or medical supports

School **75%**



Professional Clinic **59%**



Home (Administered by visiting staff) **29%**



Hospital **17%**



Daycare **17%**



Home (Administered by a parent or caregiver) **14%**

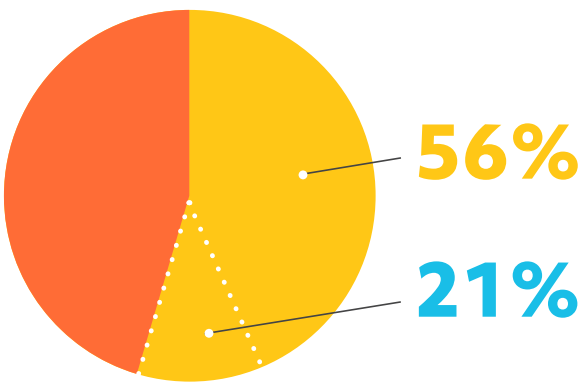


Residential programs **7%**



Average of 18 days since service disruption

Remote services and therapies



56% of families are receiving remote services, therapies or medical supports.

21% are receiving remote supports and benefiting moderately well to significantly from them.

Parent and guardian's mental and emotional health

57% of parents and guardians are feeling good overall.

97%

Percent of parents or guardians that are feeling stressed or overwhelmed due to disruptions.

96%

Percent of parents or guardians that report COVID-19 has negatively impacted their mental health.

43% of parents/guardians have taken a full or partial leave from work to take care of their child at home.

14% have brought in other individuals to help in the home, and **86%** of these families say it is helping moderately well to significantly.

Behavioral impacts

Negative impact of disruptions on symptoms, behaviors and other challenges



What's working?

These suggestions were provided from parents and guardians.

- ✓ Setting realistic expectations
- ✓ Breaks for rest, relaxation and meditation
- ✓ Pursuing hobbies and getting outside
- ✓ Cooking with family
- ✓ Enjoying time with family in person and virtually

Family quotes

"Lowering expectations. My main goal is my children not losing skills, not really looking at teaching new things. Getting outside as much as possible."

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"Over the years we have experienced some degree of uncertainty and isolation in dealing with our child's diagnosis. COVID-19 is new, but we're decently equipped to handle it."

"I'm just winging it at this point. I'm trying not to put too much added pressure on myself."

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"Telehealth is not for us. It would have been nice to hear: What do you feel is appropriate for your child and you in this time...We are in survival mode... I feel like trying to continue educating [my child] online is totally inappropriate for him."

A special thank you to the families who shared their experiences with us!

