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

Who participated?

Parents and Guardians
- 96% Female
- 43 years old on average

Their Children/Dependents
- 55% Male
- 10 years old on average (ranging from <1 year to 45 years)

Disruptions in services and therapies

60% 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

86% came from North America, and the UK.

Dependents with a genetic change
- 60% ASD
- 25% Seizures
- 85% Developmental delay

Children/Dependents have these diagnoses:
- 27% ASD
- 25% Seizures
- 85% Developmental delay

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%

60% of families report severe disruptions in services, therapies and medical supports.

489 families completed the survey, representing information collected April 1 - 7, 2020, across 59 different genetic groups and 26 countries.
These suggestions were pulled from comments that parents and guardians entered through an open-ended question in the survey.

**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% of parents and 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.

**Behavioral impacts**

- 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.

**What’s working?**

- Some suggestions are 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.”

“I’m just winging it at this point. I’m trying not to put too much added pressure on myself.”

“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.”

“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.”

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