Who participated?

Parents and Guardians
10% Female
Average age: 42 years

Children/Dependents
46% Male
Average age: 10 years

3,088 families
1,497 sent to
362 completed

Collected Aug 26, 2020 to Oct 14, 2020
Across 55 different genetic conditions and 28 countries

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

Survey 3: Development and Mental Health during COVID-19

Many hold steady in their development, but some have lost skills over the summer.

63% reported no loss of skills.
37% reported loss of skills.

Most dependents have positive mental health.
77% reported excellent, very good, or good overall emotional or mental health.

2% reported poor overall emotional or mental health.
21% reported fair overall emotional or mental health.

Of those who lost skills, most were still working on getting them back as of September.

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Mental Health

Parents and Guardians Their Children/Dependents

Many held steady in their development, but some have lost skills over the summer.

Most dependents have positive mental health.

A majority of caregivers describe their own mental health as positive.

This is similar to what was found in survey 2.

Most caregivers feel stressed or overwhelmed by the disruption in their dependent's services, therapies or medical supports.

Similar to the sleep disruption their dependents are experiencing, caregivers report their sleep to be restless.

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A majority of caregivers describe their own mental health as positive.

This is similar to what was found in survey 2.

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Similar to the sleep disruption their dependents are experiencing, caregivers report their sleep to be restless.
Survey 3: Development and Mental Health during COVID-19

Parents and Guardians
- 96% Female
- Average age: 42 years

Children/Dependents
- 4 out of 10 children were male
- A majority of caregivers describe their own mental health as positive.

Who participated?
- Development Caregivers
- Sent to 1,497 families
- Completed by 362 families
- Collected Aug 26, 2020 to Oct 14, 2020
- Across 55 different genetic conditions and 28 countries

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Survey 3: Development and Mental Health during COVID-19

Many hold steady in their development, but some have lost skills over the summer.

Off those who lost skills, most were still working on getting them back as of September.

Most dependents have positive mental health.

Overall, parents said that...

Slightly more than half of caregivers report their mental health as positive.

Most caregivers feel stressed or overwhelmed by the disruption in their dependent's services, therapies or medical supports.

Similar to the sleep disruption their dependents are experiencing, caregivers report their sleep to be restless.

Mental Health

77% reported excellent, very good, or good overall emotional or mental health.

21% reported poor overall emotional or mental health.

2% reported no change in emotional or mental health.

Mental Health Extensively

Most dependents have positive mental health.

Most caregivers feel stressed or overwhelmed by the disruption in their dependent's services, therapies or medical supports.

Similar to the sleep disruption their dependents are experiencing, caregivers report their sleep to be restless.

Mental Health

77% reported excellent, very good, or good overall emotional or mental health.

21% reported poor overall emotional or mental health.

2% reported no change in emotional or mental health.
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