

Survey 3: Development and Mental Health during COVID-19



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**

Who participated?

Parents and Guardians

90% Female

Average age: **42 years**



Their Children/Dependents



6 out of 10
children were **male**

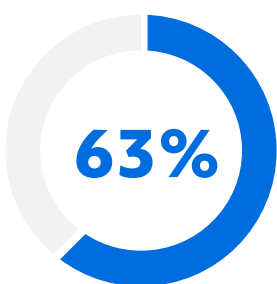
Ranging from
7 months to 45 years



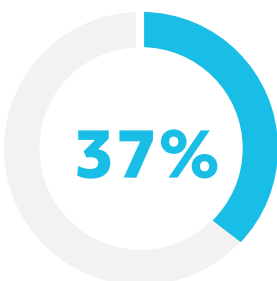
The above data has been similar for our COVID-19 surveys (I, II and III).

Development

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

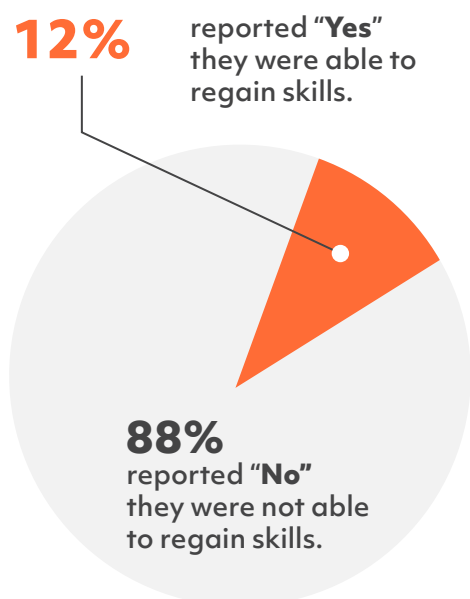


63% reported **no loss of skills.**



37% reported **loss of skills.**

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



Mental Health

Most dependents have **positive mental health**.



2% reported **poor** overall emotional or mental health.

reported **excellent, very good, or good** overall emotional or mental health.

21% reported **fair** overall emotional or mental health.

Overall, parents said that **anxiety has not been a significant concern**.

Never/Almost never **44%**

Sometimes **40%**

Often/Almost always **16%**

Half of dependents have **difficulty sleeping** at least sometimes.

49%
Never or almost never

51%
Sometimes, often or almost always



Caregivers

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

This is similar to what was found in survey 2.

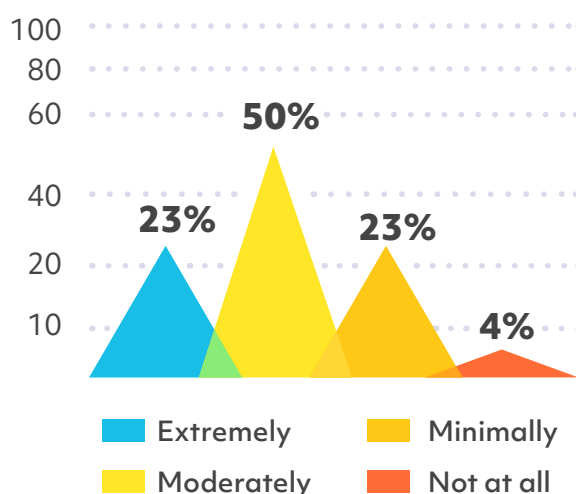


28% reported **fair** emotional or mental health.

reported **excellent, very good, or good** emotional or mental health.

10% reported **poor** emotional or 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**.

18%
Rarely or none
of the time.

33%
Some or a little
of the time.



27%
Occasionally or a
moderate amount
of the time.

22%
Most or all
of the time.

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



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