

# SIMONS SEARCHLIGHT

## Survey 6

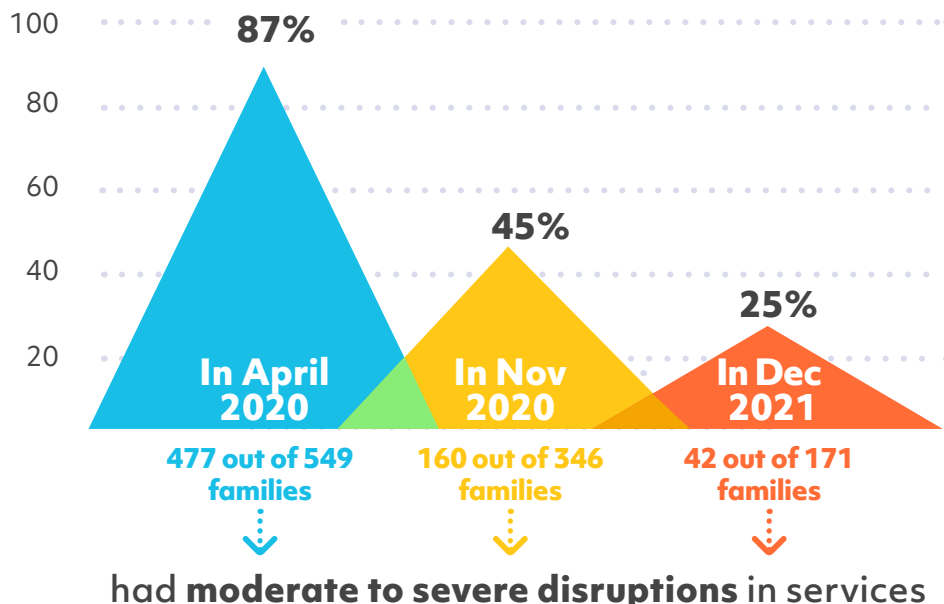
### Updates: Access to Education, Therapies, and Services during COVID-19



Sent to **545 families**  
Completed by **182 families**  
Collected **December 8–20, 2021**  
Across **43 different genetic conditions**

#### Effects on services

**Disruptions to services, therapies, or medical supports** due to COVID-19 have decreased since the beginning of the pandemic.

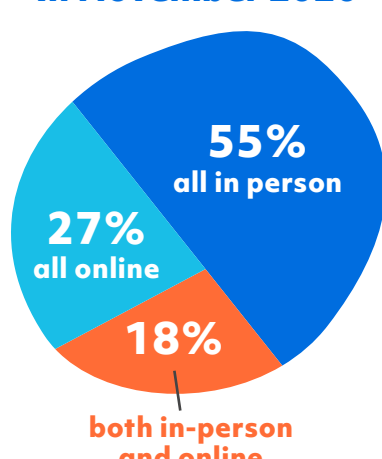


#### What school looked like

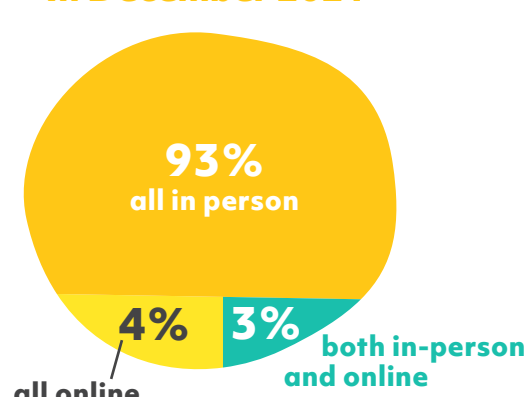


**Most dependents are attending school in person** for the 2021–2022 school year.

**In November 2020**

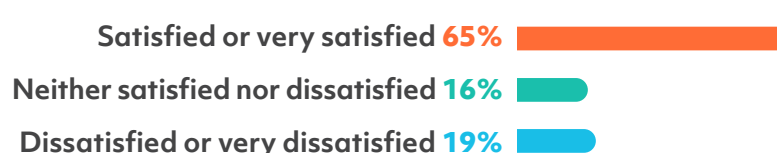


**In December 2021**

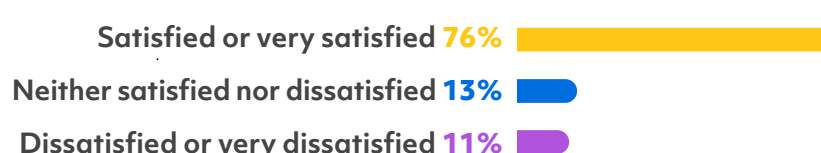


**Caregivers' satisfaction with their dependents' school experience improved.**

**In November 2020**



**In December 2021**



In December 2021, we also found that:

**89%**

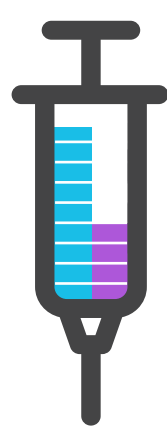
of caregivers said their child had an **individualized education plan**, or IEP

**45%**

of caregivers said that they experienced **delays in developing or updating their child's IEP** due to COVID-19

#### COVID-19 vaccine

**88%** of households have someone in their household that received the COVID-19 vaccine



**45%** of caregivers said that their dependents\* with genetic conditions have received the COVID-19 vaccine

\*This includes children in Simons Searchlight that are not yet in an eligible age group for the vaccine.

#### COVID-19 infections and concerns

**In November 2020**



of families said that someone in their household **tested positive** for COVID-19

**In December 2021**



of families said that someone in their household **tested positive** for COVID-19

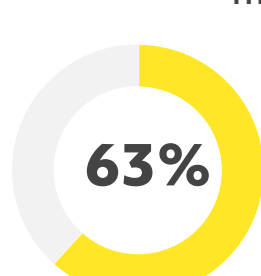
As of December 2021, **21 out of 182 participants with a genetic condition** have tested positive for COVID-19. **Only 2 out of these 21 people who had COVID-19 were hospitalized** due to the disease.

**182**  
participants

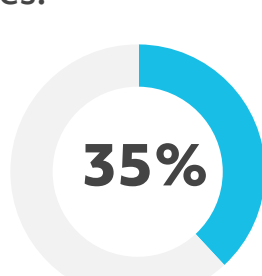
**21**  
tested positive

**2**  
hospitalized

**Caregivers** are much more concerned about their dependents than themselves.



of caregivers are moderately to severely concerned about COVID-19 and the health of their **dependents with the genetic condition**



of caregivers are moderately to severely concerned about COVID-19 and **their own health**

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

[SimonsSearchlight.org](https://SimonsSearchlight.org)

