Survey 2: Impact of COVID-19 on medical supports and caregiver mental health

Who participated?
Participants by Gene Group

Effects on services
Improved caregiver mental and emotional health

Caregivers reported some improvements in their emotional and mental health due to COVID-19.

Medical provider info

Use of emergency room services

Few caregivers had trouble accessing medications.

Medical experience and medications

A majority, up to 90%, said they accessed these providers through telehealth/telemedicine, but some received services at home, in clinic or could not access these medical services.

One participant from each of the following genes

15q11.2 BP1-BP2 deletion
3q29 deletion
ANKRD11 (KBG)
AUTS2
BCL11A
CASZ1
CHD3
CHD8
CTBP1
DNMT3A (Tatton-Brown-Rahman)
FOXP1
GIGYF1
HNRNPU
KMT2E (O'Donnell-Luria-Rodan)
MBD5
NLGN4x
NRXN1
POGZ (White-Sutton)
PPP2R5C
PTCHD1
PURA
SHANK3
TAOK1
USP9X
VPS13B (Cohen Syndrome)

Since COVID-19, some caregivers saw an increase in behavior issues for the following:

Repetitive behaviors 36%
Aggression 28%
Self-injury 13%
Anxiety 40%
Sleep disruption 42%

During COVID-19 some dependents required access to physicians and other medical providers.

During COVID-19 54 caregivers considered taking their child to the emergency room, and they decided:

Use of emergency room services

Refrained to participate in daily activities 40%

Volunteered to take part in research 20%

Several caregivers had trouble accessing medications:

During COVID-19 70% of families have had disruptions in services for their children.

Percent of services that are being offered to caregivers online:

Employment impact

Most did not report a negative impact on finances due to COVID-19.

Caregivers reported some improvements in employment but did not report a major change in their financial status due to COVID-19.

Percent of caregivers who had moderate to severe disruptions in services for their children:

Recreational services 21%
Speech and language therapy 75%
Special education services 67%
Mental health services 85%
PT/OT 64%
Early intervention 61%
Adult disability services 32%
ABA/behavioral therapy 47%

Percent of families that are receiving online or remote delivery of services, an increase since the first survey.

Percent of families feel moderately to extremely stressed about the disruption of services for their child:

Percent of families report feeling hopeful moderately to most of the time:

Medical experience and medications

Several caregivers had trouble accessing medications:

During COVID-19, some families described the following impacts on employment and finances:

42% of families are receiving online or remote delivery of services, an increase since the first survey.

70% of families have had disruptions in services for their children.

77% of families feel moderately to extremely stressed about the disruption of services for their child.

During COVID-19 some families described the following impacts on employment and finances:

42% negative impact on employment
33% negative impact on finances
22% trouble accessing medications
65% trouble accessing medications
34% trouble accessing medications

Caregivers reported some improvements in employment, but did not report a major change in their financial status due to COVID-19.

70% of families have had disruptions in services for their children.

Percent of services that are being offered to caregivers online:

Employment impact

Most did not report a negative impact on finances due to COVID-19.

Caregivers reported some improvements in employment but did not report a major change in their financial status due to COVID-19.

Percent of caregivers who had moderate to severe disruptions in services for their children:

Recreational services 21%
Speech and language therapy 75%
Special education services 67%
Mental health services 85%
PT/OT 64%
Early intervention 61%
Adult disability services 32%
ABA/behavioral therapy 47%

Percent of families that are receiving online or remote delivery of services, an increase since the first survey.

Percent of families feel moderately to extremely stressed about the disruption of services for their child:

Percent of families report feeling hopeful moderately to most of the time:

Medical experience and medications

Several caregivers had trouble accessing medications:

During COVID-19, some families described the following impacts on employment and finances:

42% negative impact on employment
33% negative impact on finances
22% trouble accessing medications
65% trouble accessing medications
34% trouble accessing medications

Caregivers reported some improvements in employment, but did not report a major change in their financial status due to COVID-19.

70% of families have had disruptions in services for their children.

77% of families feel moderately to extremely stressed about the disruption of services for their child.

During COVID-19 some families described the following impacts on employment and finances:

42% negative impact on employment
33% negative impact on finances
22% trouble accessing medications
65% trouble accessing medications
34% trouble accessing medications

Caregivers reported some improvements in employment, but did not report a major change in their financial status due to COVID-19.
Survey 2: Impact of COVID-19 on medical supports and caregiver mental health

Who participated?
Participants by Gene Group

Effects on services
Improved caregiver mental and emotional health

Employment impact
Caregivers reported some impact on employment but most did not report a negative impact on finances due to COVID-19.

Medical provider info

Use of emergency room services

Medical experience and medications

A special thank you to the families who shared their experiences.
Survey 2: Impact of COVID-19 on medical supports and caregiver mental health

Who participated?
Participants by Gene Group

Effects on services

- Improved caregiver mental and emotional health
- Percent of services that are being offered online or remote delivery of services, an increase since the first survey.
- Caregivers reported some impacts on employment and finances due to COVID-19.

Medical provider info

- In April, 54 caregivers considered taking their child to the emergency room, and they decided:
  - Did not go to the ER because of fear of COVID-19: 39%
  - Used telehealth instead: 20%
  - Went after a delay: 13%
  - Called a doctor: 46%
  - Went to ER did not delay: 20%

Medical experience and medications

- Several caregivers have trouble accessing medications:
  - For routine symptom management: 65%
  - Scheduled procedures/care may have been postponed: 34%

Use of emergency room services

During COVID-19 many dependents required access to physicians and other medical providers.

Caregivers reported some impacts on employment and finances due to COVID-19.

Percent of services that are being offered online or remote delivery of services, an increase since the first survey.