

**The CoRonavirus Health Impact Survey (CRISIS) - Adapted for Autism and Related
Neurodevelopmental conditions (AFAR)- V0.5.1
Parent/Caregiver/Informant Baseline Form (21+ years)**

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Development team for core CRISIS Survey:

The CRISIS questionnaires were developed through a collaborative effort between the research teams of Kathleen Merikangas and Argyris Stringaris at the National Institute of Mental Health Intramural Research Program Mood Spectrum Collaboration, and those of Michael P. Milham at the Child Mind Institute and the NYS Nathan S. Kline Institute for Psychiatric Research.

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Development team for the CRISIS AFAR Survey:

This adaptation was aimed to assess the specific needs and changes related to the Coronavirus/COVID-19 crisis in adults with autism and related neurodevelopmental conditions. The general structure of the core CRISIS forms was maintained, items focusing on services, adaptive key behaviors, as well as associated symptoms relevant for autism and related conditions were added. A few items not considered specific were removed, others reworded to better fit the target population (a detailed summary is available upon request to Adriana.DiMartino@chidmind.org).

Primary Content Developers: Adriana Di Martino, Louise Gallagher, Stelios Georgiades, Panagiota (Neny) Pervanidou, Audrey Thurm, Bethany Vibert. The section entitled School and Services was based largely on questions selected from the CARING through COVID questionnaire developed by Shafali Jeste and colleagues at University of California, Los Angeles, and has been slightly adapted.

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The CRISIS team encourages advanced notification of any media, scientific reports or publications of data that have been collected with the core CRISIS and the present adaptation (merikank@mail.nih.gov and Adriana.DiMartino@childmind.org, respectively) though this is not required. We also encourage voluntary data sharing for the purpose of psychometric studies that will be led by Dr. Stringaris (argyris.stringaris@nih.gov). Please, contact Adriana.DiMartino@chidmind.org if you would like to make de-identified data contributions for the CRISIS AFAR

The CoRoNaVirus Health Impact Survey (CRISIS)-AFAR V0.5.1: Parent Caregiver Baseline
Form for 21+

Identification Number: _____

Country:

State/Province/Region:

Your age (years):

Age of your family member with a developmental disability* (years):

**Developmental disability refers to developmental conditions that begin early in life with long-standing impacts on learning, language and communication, social interaction, motor functioning, and behaviour. Examples include (but are not limited to) autism, intellectual disability, learning disorders, attention-deficit/hyperactivity disorder, cerebral palsy, alone or co-occurring. When referring to "family member" in the questions below, we are referring to "your family member with a developmental disability".*

BACKGROUND:

First, before we get started with the main questions, we would like to collect some background information about your family member with a developmental disability.

1. What is your relationship to your family member with a developmental disability?
 - a. Mother
 - b. Father
 - c. Grandparent
 - d. Aunt/Uncle
 - e. Foster Parent
 - f. Sibling
 - g. Other: Specify _____
2. Please specify the sex of your family member with a developmental disability at birth:
 - a. Male
 - b. Female
 - c. Other _____
3. Please specify the gender of your family member with a developmental disability:
 - a. Man
 - b. Woman
 - c. Trans man
 - d. Trans woman
 - e. Non-binary
 - f. Identity not listed (please specify: _____)

Commented [ADM1]: In redcap this section can be the ID# or name(s) of completers or of their child, and/or their email address. The investigator should edit their redcap instrument in accordance to their IRB protocol. If PHI (e.g., names email) were collected only authorized trained staff can access it in a given institution, data should be deidentified before data sharing.

4. Thinking about what you know of the family history of your family member with a developmental disability, which of the following best describes the geographic regions from where their ancestors (i.e. great-great-grandparents) came from? You may select as many choices as needed.

- a. England, Ireland, Scotland or Wales
- b. Australia – not of Aboriginal or Torres Strait Islander descent
- c. Australia – of Aboriginal or Torres Strait Islander descent
- d. New Zealand – not of Maori descent
- e. New Zealand – of Maori descent
- f. Northern Europe including Sweden, Norway, Finland and surrounding countries
- g. Western Europe including France, Germany, the Netherlands and surrounding countries
- h. Eastern Europe, including Russia, Poland, Hungary and surrounding countries
- i. Southern Europe including Italy, Greece, Spain, Portugal and surrounding countries
- j. Middle East including Lebanon, Turkey and surrounding countries
- k. Eastern Asia including China, Japan, South Korea, North Korea, Taiwan and Hong Kong
- l. South-East Asia including Thailand, Malaysia, Indonesia, Singapore and surrounding countries
- m. South Asia including India, Pakistan, Sri Lanka and surrounding countries
- n. Polynesia, Micronesia or Melanesia including Tonga, Fiji, Papua New Guinea and surrounding countries
- o. Africa
- p. North America - not of First Nations, Native American, Inuit or Métis descent
- q. North America - of First Nations, Native American, Inuit or Métis descent
- r. Central or South America
- s. Don't know
- t. Other

5. Is your family member with a developmental disability of Hispanic or Latino descent - that is, Mexican, Mexican American, Chicano, Puerto Rican, Cuban, South or Central American or other Spanish culture or origin?

- a. Yes
- b. No

6. What is the highest level of education your family member with a developmental disability completed?

- a. Some grade school
- b. Some high school
- c. High school diploma or GED (General Educational Development test)
- d. Some college or 2-year degree

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- e. 4-year college or university graduate
- f. Some school beyond college
- g. Graduate (e.g. master's, PhD) or professional degree

7. What is the highest level of education YOU completed?

- a. Some grade school
- b. Some high school
- c. High school diploma or GED (General Educational Development test)
- d. Some college or 2-year degree
- e. 4-year college or university graduate
- f. Some school beyond college
- g. Graduate (e.g. master's, PhD) or professional degree

8. What is the highest level of education the second parent/caregiver of your family member with a developmental disability completed?

- a. Some grade school
- b. Some high school
- c. High school diploma or GED (General Educational Development test)
- d. Some college or 2-year degree
- e. 4-year college or university graduate
- f. Some school beyond college
- g. Graduate (e.g. master's, PhD) or professional degree
- h. No second parent/caregiver

9. Which best describes the area in which your family member with a developmental disability lives?

- a. Large city
- b. Suburbs of a large city
- c. Small city
- d. Town or village
- e. Rural area

10. How does your family member with a developmental disability USUALLY spend the majority of their day? Select all that apply.

- a. Attends college/university part time
- b. Attends college/university full time
- c. Works part time
- d. Works full time
- e. Attends day program
- f. Volunteers
- g. No structured day time activity

11. Where does your family member with a developmental disability live?

- a. By themselves and fully independent
- b. By themselves and partially independent, requiring some essential support

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- c. In a group home
- d. In an institutional setting that is not a group home (e.g., hospital, nursing home)
- e. With me
- f. With other family members
- g. With friends or other roommates

12. How many people currently live in the home of your family member with a developmental disability (excluding your family member with a developmental disability)? ____

13. Please specify their relationship(s) to your family member with a developmental disability (check all that apply):

- a. One parent
- b. Two parents
- c. Grandparents
- d. Siblings
- e. Other children
- f. Other relatives
- g. Unrelated person

14. Are any adults living in the home an ESSENTIAL WORKER (e.g., healthcare, delivery worker, store worker, security, building maintenance)? (Yes/No)

- a. If yes,
 - **Do they come home each day?**
 - Yes
 - No, separated due to COVID-19
 - No separated due to other reasons
 - **Are they a FIRST RESPONDER, HEALTHCARE PROVIDER or OTHER WORKER in a facility treating COVID-19? (Yes/No)**

15. How many rooms (total) are in the home of your family member with a developmental disability? ____

16. Is your family member with a developmental disability covered by health insurance?

- a. Yes, military
- b. Yes, employer-sponsored
- c. Yes, individual
- d. Yes, Medicare
- e. Yes, Medicaid or CHIP
- f. Yes, other
- g. No

17. In the 3 months prior to the Coronavirus/COVID-19 crisis in your area, did you or your family receive money from government assistance programs like welfare, Aid to Families with Dependent Children, General Assistance, or Temporary Assistance for Needy Families?

- a. Yes
- b. No

18. How tall is your family member with a developmental disability? ____ centimeters(cm)/inches(in)

19. How much does your family member with a developmental disability weigh? ____ kilograms(kg)/pounds(lbs)

20. How would you rate the overall physical health of your family member with a developmental disability?

- a. Excellent
- b. Very Good
- c. Good
- d. Fair
- e. Poor

21. How would you rate the overall mental/emotional health of your family member with a developmental disability?

- a. Excellent
- b. Very Good
- c. Good
- d. Fair
- e. Poor

22. Has a health or educational professional ever told you that your family member with a developmental disability had any of the following health conditions (check all that apply)?

- a. Seasonal allergies
- b. Asthma or other lung problems
- c. Heart problems
- d. Kidney problems
- e. Immune disorder
- f. Diabetes or high blood sugar
- g. Cancer
- h. Arthritis
- i. Frequent or very bad headaches
- j. Epilepsy or seizures
- k. Serious stomach or bowel problems
- l. Serious acne or skin problems
- m. Vision problems
- n. Hearing problems

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- o. Obsessive compulsive disorder
- p. Emotional or mental health problems such as Depression or Anxiety
- q. Problems with alcohol or drugs
- r. Intellectual disability
- s. Autism spectrum disorder
- t. Learning disorder
- u. Attention-deficit/hyperactivity disorder
- v. Other problems requiring special education services
- w. Other neurodevelopmental conditions
- x. Developmental delay
- y. Known genetic conditions
- z. None of the above

22a. If you checked any between v and y, [insert] please specify_____

22b. *[If one or more of the response options between r and x on question 22 were selected, then ask]:* **How much language did your family member with a developmental disability spontaneously use on a daily basis for 1 month consistently prior to the COVID-19 crisis in your area?**

- i. No words/does not speak
- ii. Uses single words meaningfully (for example, to request)
- iii. Combines three words together into short sentences
- iv. Uses longer sentences of his/her own and is able to tell you something that happened

CORONAVIRUS/COVID-19 HEALTH/EXPOSURE STATUS

During the **PAST TWO WEEKS:**

23.... has your family member been exposed to someone likely to have Coronavirus/COVID-19? (check all that apply)

- a. Yes, someone with positive test
- b. Yes, someone with medical diagnosis, but no test
- c. Yes, someone with possible symptoms, but no diagnosis by doctor
- d. No, not to my knowledge

24.... has your family member been suspected of having Coronavirus/COVID-19 infection?

- a. Yes, have had positive test
- b. Yes, medical diagnosis, but no test
- c. Yes, has had some possible symptoms, but no diagnosis by doctor
- d. No symptoms or signs

25.... has your family member had any of the following symptoms? (check all that apply)

- a. Fever

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- b. Cough
- c. Shortness of breath
- d. Sore throat
- e. Fatigue
- f. Loss of taste or smell
- g. Eye infection
- h. Other ____
- i. None of the above

26.... has anyone in your family member's family been diagnosed with Coronavirus/COVID-19? (check all that apply)

- a. Yes, member of household
- b. Yes, non-household member
- c. No

27.... have any of the following happened to your family member because of Coronavirus/COVID-19 pandemic? (check all that apply)

- a. Fallen ill physically
- b. Hospitalized
- c. Put into self-quarantine with symptoms
- d. Put into self-quarantine without symptoms (e.g., due to possible exposure)
- e. Lost or been laid off from job
- f. Reduced ability to earn money
- g. Passed away
- h. None of the above

During the PAST TWO WEEKS, how worried has your family member been about:

28..... being infected by Coronavirus / having COVID-19?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

29.... his/her friends or family being infected by Coronavirus / having COVID-19?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

30.... his/her *physical health* being influenced by Coronavirus/COVID-19?

- a. Not at all
- b. Slightly
- c. Moderately

- d. Very
- e. Extremely

31.... his/her *mental/emotional health* being influenced by Coronavirus/COVID-19?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

32.How much is your family member asking questions, reading, watching content, or talking about Coronavirus/COVID-19?

- a. Never
- b. Rarely
- c. Occasionally
- d. Often
- e. Most of the time
- f. Not applicable due to my family member's limited communication

33.Has the Coronavirus/COVID-19 crisis in your area led to any positive changes in your family member's life?

- a. None
- b. Only a few
- c. Some

- If answered b or c to question 33, please specify what these positive changes are: _____

LIFE CHANGES DUE TO THE CORONAVIRUS/COVID-19 CRISIS IN THE LAST TWO WEEKS:

During the PAST TWO WEEKS:

34.... how much time has your family member spent going outside of the home (e.g., going to stores, parks, etc.)?

- a. Not at all
- b. 1-2 days per week
- c. A few days per week
- d. Several days per week
- e. Every day

35.... how stressful have the restrictions on leaving home been for your family member?

- a. Not at all / no changes
- b. Slightly
- c. Moderately

- d. Very
- e. Extremely

36. ...has cancellation of important events (such as birthday parties, graduation, prom, vacation, etc.) been difficult for your family member?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

37.... to what degree have changes related to the Coronavirus/COVID-19 crisis in your area created financial problems for your family member or your family?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

38.... to what degree is your family member concerned about the stability of his/her living situation?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely
- f. Unknown due to my family member's limited communication

39.... to what degree is your family member worried whether his/her food would run out because of a lack of money?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely
- f. Unknown due to my family member's limited communication

40.How hopeful is your family member that the Coronavirus/COVID-19 crisis in your area will end soon?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely
- f. Unknown due to my family member's limited communication

Thank you for completing the questions above.

In order to better assess the COVID-19 crisis impact on your family member, we would first like to ask about your family member's daily behaviors and sleep during the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area, and then we would like to ask about the **LAST TWO WEEKS**.

DAILY BEHAVIORS (THREE MONTHS PRIOR TO CRISIS)

During the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area, how independently did your family member ...

41.... entertain self appropriately for at least 20 minutes?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

42....structure/initiate daily activities (e.g., started and completed schoolwork/homework/chores, followed general schedule of completing activities)?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

43.... complete self-care activities (e.g., got dressed/changed independently/brushed teeth/bathe/shower daily) and/or start day's activities?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

44....manage mealtime and food-related needs (e.g., preparing, organizing, and cleaning up)?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

During the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area

45.... on average, what time did your family member go to bed on WEEKDAYS?

- a. Before 8 pm
- b. 8 pm-10 pm
- c. 10 pm-12 am
- d. After midnight

46.... on average, what time did your family member go to bed on WEEKENDS?

- a. Before 8 pm
- b. 8 pm-10 pm
- c. 10 pm-12 am
- d. After midnight

47.... on average, how many hours per night did your family member sleep on WEEKDAYS?

- a. <6 hours
- b. 6-8 hours
- c. 8-10 hours
- d. >10 hours

48.... on average, how many hours per night did your family member sleep on WEEKENDS?

- a. <6 hours
- b. 6-8 hours
- c. 8-10 hours
- d. >10 hours

49....on average, did your family member have difficulties falling asleep (e.g., within 20 minutes) after going to bed?

- a. Not at all
- b. Rarely (less than once a week)
- c. Occasionally (once or twice a week)
- d. Often (three or more times a week but not daily)
- e. Regularly (daily)

50....on average, did your family member wake up and remain awake during the night after falling asleep?

- a. Not at all
- b. Rarely (less than once a week)
- c. Occasionally (once or twice a week)
- d. Often (three or more times a week but not daily)
- e. Regularly (daily)

51.... how many days per week did your family member exercise (e.g., increased heart rate, increased rate of breathing) for at least 30 minutes?

- a. None
- b. 1-2 days
- c. 3-4 days

- d. 5-6 days
- e. Daily

52.... how many days per week did your family member spend time outdoors?

- a. None
- b. 1-2 days
- c. 3-4 days
- d. 5-6 days
- e. Daily

BEHAVIORS AND INTERESTS (THREE MONTHS PRIOR TO CRISIS)

During the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area, how frequently did your family member:

53....engage in repetitive motor mannerisms/movements (e.g., repetitive movements of the whole body, or just with their hands and fingers)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

54....engage in sensory seeking behaviors (e.g., visually inspecting things, touching or feeling things for a long time)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

55....engage in other rituals or routines?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

56....adjust easily to changes in daily routines (e.g., changes in time, location, order, or occurrence of regularly scheduled or typical daily activities such as appointments, mealtimes, or the addition of unexpected events/activities)?

- a. Not at all
- b. Rarely
- c. Occasionally

- d. Often
- e. Regularly

57....require family members and others he/she interacts with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior (e.g., takes longer to complete tasks, changes schedule to accommodate your family member)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

58....engage in an activity related to a highly restricted, strong interest (e.g., play with the toy/topic, talk about the toy/topic, watch content related to that toy/topic)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

During the THREE MONTHS PRIOR to the onset of the Coronavirus/COVID-19 crisis in your area

59.... have any of the following been a significant problem in your family member's behavior (that was not already controlled by treatment before)?

Please check all that apply:

- a. Hyperactivity
- b. Difficulty staying on task
- c. Getting angry or losing temper easily
- d. Verbal aggression
- e. Physical aggression to others or to property
- f. Deliberately injuring self
- g. Arguing often
- h. Crying easily
- i. Being excessively worried about social situations (e.g., going to a planned activity, speaking publicly)
- j. Being excessively worried on separating from parent/ caregiver
- k. Seeming excessively fearful
- l. None of the above

59a. For each symptom checked, follow up with:

How much of a problem has this been for your family member?

- m. Slightly
- n. Moderately

- o. Very Much
- p. A lot

MEDIA USE (THREE MONTHS PRIOR TO CRISIS)

During the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area, how much time per day did your family member spend:

60....watching TV or digital media (e.g., Netflix, YouTube, web surfing)?

- a. No TV or digital media
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

61....using social media (e.g., Facetime, Facebook, Instagram, Snapchat, Twitter, TikTok)?

- a. No social media
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

62....playing video games?

- a. No video games
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

During the **THREE MONTHS PRIOR** to the onset of the Coronavirus/COVID-19 crisis in your area, how frequently did your family member:

63....engage in online/text/email/phone call/video chat interactions with peers outside the household (other than video games)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly
- f. Not Applicable (e.g., no opportunity)

64....engage in online/text/email/phone call/video chat interactions with adults outside the home, such as extended family members (not including therapists or teachers)?

- a. Not at all

- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly
- f. Not Applicable (e.g., no opportunity)

Thank you for answering the questions above.

Now we would like to ask you about your family member's daily behaviors and sleep during the PAST TWO WEEKS.

DAILY BEHAVIORS (PAST TWO WEEKS)

During the PAST TWO WEEKS, how independently did your family member:

65....entertain self appropriately for at least 20 minutes ?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

66....structure/initiate daily activities (e.g., started and completed schoolwork/homework/chores, followed general schedule of completing activities)?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

67....complete self-care activities (e.g., got dressed/changed independently/brushed teeth/bathe/shower daily) and/or start day's activities?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

68....manage mealtime and food related needs (e.g., preparing, organizing, and cleaning up)?

- a. Independently (without support, prompting, or supervision)
- b. With moderate supervision (some verbal and/or visual reminders)
- c. With close supervision (support including step-by-step instruction)
- d. Not at all

DURING THE PAST 2 WEEKS

69....on average, what time did your family member go to bed on WEEKDAYS?

- a. Before 8 pm
- b. 8 pm-10 pm
- c. 10 pm-12 am
- d. After midnight

70.... on average, what time did your family member go to bed on WEEKENDS?

- a. Before 8 pm
- b. 8 pm-10 pm
- c. 10 pm-12 am
- d. After midnight

71.... on average, how many hours per night did your family member sleep on WEEKDAYS?

- a. <6 hours
- b. 6-8 hours
- c. 8-10 hours
- d. >10 hours

72.... on average, how many hours per night did your family member sleep on WEEKENDS?

- a. <6 hours
- b. 6-8 hours
- c. 8-10 hours
- d. >10 hours

73....on average, did your family member have difficulties falling asleep (e.g. within 20 minutes) after going to bed?

- a. Not at all
- b. Rarely (less than once a week)
- c. Occasionally (once or twice a week)
- d. Often (three or more times a week but not daily)
- e. Regularly (daily)

74....on average, did your family member wake up and remain awake during the night after falling asleep?

- a. Not at all
- b. Rarely (less than once a week)
- c. Occasionally (once or twice a week)
- d. Often (three or more times a week but not daily)
- e. Regularly (daily)

75.... how many days per week did your family member exercise (e.g., increased heart rate, increased rate of breathing) for at least 30 minutes?

- a. None
- b. 1-2 days
- c. 3-4 days

- d. 5-6 days
- e. Daily

76.... how many days per week did your family member spend time outdoors?

- a. None
- b. 1-2 days
- c. 3-4 days
- d. 5-6 days
- e. Daily

BEHAVIORS AND INTERESTS (PAST TWO WEEKS)

During the **PAST TWO WEEKS**, how frequently did your family member:

77....engage in repetitive motor mannerisms/movements (e.g., repetitive movements of the whole body, or just with their hands and fingers)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

78....engage in sensory seeking behaviors (e.g., visually inspecting things, touching or feeling things for a long time)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

79....engage in in other rituals or routines?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

80....adjust easily to changes in daily routines (e.g., changes in time, location, order, or occurrence of regularly scheduled or typical daily activities such as appointments, mealtimes, or the addition of unexpected events/activities)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

81....require family members and others he/she interacts with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior (e.g., takes longer to complete tasks, changes schedule to accommodate your family member)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

82....engage in an activity related to a highly restricted, strong interest (e.g., play with the toy/topic, talk about the toy/topic, watch content related to that toy/topic)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

DURING THE PAST TWO WEEKS

83....have any of the following been a significant problem in your family member's behavior (that was not controlled by treatment)? Please check all that apply:

- a. Hyperactivity
- b. Difficulty staying on task
- c. Getting angry or losing temper easily
- d. Verbal aggression
- e. Physical aggression to others or to property
- f. Deliberately injuring self
- g. Arguing often
- h. Crying easily
- i. Being excessively worried about social situations (e.g., going to a planned activity, speaking publicly)
- j. Being excessively worried on separating from parent/ caregiver
- k. Seeming excessively fearful
- l. None of the above

83a. For each symptom checked, follow up with:

During the past 2 weeks, how much of a problem has this been for your family member?

- a. Slightly
- b. Moderately
- c. Very Much
- d. A lot

MEDIA USE (PAST TWO WEEKS)

During the **PAST TWO WEEKS**, how much time per day did your family member spend:

84.... watching TV or digital media (e.g., Netflix, YouTube, web surfing)?

- a. No TV or digital media
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

85.... using social media (e.g., Facetime, Facebook, Instagram, Snapchat, Twitter, TikTok)?

- a. No social media
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

86.... playing video games?

- a. No video games
- b. Under 1 hour
- c. 1-3 hours
- d. 4-6 hours
- e. More than 6 hours

During the **PAST TWO WEEKS** how frequently did your family member:

87....engage in online/text/email/phone call/video chat interactions with peers outside the household (other than video games)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly
- f. Not Applicable (e.g., no opportunity)

88....engage in online/text/email/phone call/video chat interactions with adults outside the home, such as extended family members (not including therapists or teachers)?

- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often

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- e. Regularly
- f. Not Applicable (e.g., no opportunity)

SERVICES

Thank you for answering the questions above.
Now we would like to ask you about services that may have been affected since the coronavirus/COVID19 crisis in your area.

89. How has the access to the following interventions or services that your family member regularly receives been affected by the coronavirus (COVID-19) crisis?

	My family member continues to receive this service (may be modified) (1)	My family member has lost access and has not received this service since COVID-19 (2)	My family member did not regularly receive this service before (3)
Speech Therapy (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapy (OT) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Therapy (PT) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Applied Behavior Analysis Therapy (ABA Therapy) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Skills Therapy (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General psychology / Counseling (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical visits (e.g. Psychiatry / Developmental Pediatrics / Neurology etc.) (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational therapy (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vocational Support (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

89a. [For each service above, if option (1) is selected]:

Please Specify how [insert service name] is now provided:

- Using telehealth (Zoom, Skype, phone conversations)
- Through emails and materials sent to my family member's home
- By a teacher, behaviorist, or therapist coming to my family member's home

- d. Through in-person appointments outside of the home

89b. *[For each service above, if in question 89a option (a) is selected, then ask]:*
for the [specify the service depending on prior answer with if logic] that your family member is now receiving via telehealth (e.g., Zoom, Skype, phone conversations), how helpful have you found these accommodations?

- a. Not helpful at all
- b. A little helpful
- c. Somewhat helpful
- d. Extremely helpful

89c. *[For each service above, if in questions 89a option (b) is selected, then ask]:*
for the [specify the service depending on prior answer with if logic] that your family member is now receiving via emails or materials sent home, how helpful have you found these accommodations?

- a. Not helpful at all
- b. A little helpful
- c. Somewhat helpful
- d. Extremely helpful

90. Has your family member needed to access any of the following providers since the coronavirus (COVID-19) crisis and how did they do so?

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	My family member has not needed access to this type of provider (1)	Yes, my family member has accessed through telehealth or telemedicine (2)	Yes, my family member has accessed through at- home appointments (3)	Yes, my family member has accessed through in- person office appointments (4)	My family member could not access this provider (5)
Family Doctor / General Pediatrician (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatry (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurology / Developmental Pediatrician (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastroenterology (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychology (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other subspecialties (such as endocrinology, dentistry) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**90a. Please tell us more about what you find helpful / not helpful about
telehealth services, if your family member has received them: _____[TEXT BOX]**

91. Since the coronavirus (COVID-19) crisis, what of the following have you experienced overall? Please select all that apply.

- a. My family member's routine appointments have been canceled or postponed.
- b. My family member's scheduled procedures or treatments have been canceled or postponed.
- c. I have had difficulty reaching or speaking to my family member's doctor(s).
- d. I have had trouble accessing my family member's medications or getting prescriptions filled.
- e. I have had trouble managing or administering my family member's medications.
- f. I have trouble affording my family member's medications, treatments, or therapy.
- g. My family member has lost access to a clinical trial.
- h. Other (Please specify)

- i. None of the above

92. Is your family member prescribed any medications for *mental health* or *behavior* concern? (Yes/No)

a. If Yes:

92a. Which options would be the most helpful to best manage medications for your family member? (check all that apply)

- 1. Reminders or notifications to administer medication
- 2. Help with cost of medications
- 3. Access to refills or having enough medication at home
- 4. Help adjusting the dose of medication
- 5. Other (Please specify)
- 6. None of the above

93. Is your family member prescribed any other medications for *physical* health? (Yes/No)

a. If Yes:

93a. Which options would be the most helpful to best manage medications for your family member (check all that apply)

- 1. Reminders or notifications to administer medication
- 2. Help with cost of medications
- 3. Access to refills or having enough medication at home
- 4. Help adjusting the dose of medication
- 5. Other (Please specify)
- 6. None of the above

GENERAL IMPACT

94. Which one of the following statements best describes the current status of your family? (Please check one).

- a. Everything is fine, my family and I are not in crisis at all.
- b. Everything is fine, but sometimes we have our difficulties.
- c. Things are sometimes stressful, but we can deal with problems if they arise.
- d. Things are often stressful, but we are managing to deal with problems when they arise.
- e. Things are very stressful, but we are getting by with a lot of effort.
- f. We have to work extremely hard every moment of every day to avoid having a crisis.
- g. We won't be able to handle things soon. If one more thing goes wrong - we will be in crisis.
- h. We are currently in crisis but are dealing with it ourselves.
- i. We are currently in crisis and have asked for help from crisis services. (Emergency room, hospital, community crisis supports).
- j. We are currently in crisis, and it could not get any worse.

95. Is there someone else in the family for whom you are also the major caregiver? *For example, this could be a baby or small child, an elderly parent, a spouse who is unwell, someone else with a disability, etc.* **(Yes/No)**

a. If yes:

95a. Please rate how these additional responsibilities affect your ability to provide care for your family member with a developmental disability

- 1. No impact
- 2. Little impact
- 3. Some impact
- 4. Serious impact
- 5. Severe impact

ADDITIONAL CONCERNS AND COMMENTS

Please describe anything else that concerns you about the impact of Coronavirus/COVID-19 on your family member.

[TEXT BOX]

Please provide any comments that you would like to share about this survey and/or related topics.

[TEXT BOX]