

**The CoRoNaVirus Health Impact Survey (CRISIS) - Adapted For Autism and Related  
Neurodevelopmental conditions (AFAR)- V0.6.1**  
*Parent/Caregiver/Informant Follow-Up 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](mailto:Adriana.DiMartino@chidmind.org)).

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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](mailto:merikank@mail.nih.gov) and [Adriana.DiMartino@childmind.org](mailto: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](mailto:argyris.stringaris@nih.gov)). Please, contact [Adriana.DiMartino@chidmind.org](mailto:Adriana.DiMartino@chidmind.org) if you would like to make de-identified data contributions for the CRISIS AFAR

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Identification Number: \_\_\_\_\_

You may have completed a survey similar to this one before. At this time, we are interested in learning how things are going now. Accordingly, we made a shorter survey for this purpose. We appreciate your time for completing this survey.

**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.

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:

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 \_\_\_\_\_

#### UPDATED CORONAVIRUS/COVID-19 HEALTH/EXPOSURE STATUS

During the **PAST TWO WEEKS**:

2. ... 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
3. ... 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

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- c. Yes, has had some possible symptoms, but no diagnosis by doctor
  - d. No symptoms or signs
4. ... has your family member had any of the following symptoms? (check all that apply)
- a. Fever
  - 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
5. ... 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
6. ... 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:

7. .... being infected by Coronavirus / having COVID-19?
- a. Not at all
  - b. Slightly
  - c. Moderately
  - d. Very
  - e. Extremely
8. ... his/her friends or family being infected by Coronavirus / having COVID-19?
- a. Not at all
  - b. Slightly
  - c. Moderately
  - d. Very
  - e. Extremely
9. ... his/her *physical health* being influenced by Coronavirus/COVID-19?
- a. Not at all
  - b. Slightly

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- c. Moderately
- d. Very
- e. Extremely

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

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

**11. 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

**12. 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 12, please specify what these positive changes are: \_\_\_\_\_

**13. If a vaccine for COVID-19 becomes available how likely are you to have your family member vaccinated?**

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

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

**During the PAST TWO WEEKS:**

**14. ... 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

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- 15. ... 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
  - f. No ongoing restrictions
- 16. ... 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
- 17. ... 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
- 18. ... 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
- 19. ... 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
- 20. 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! Now we would like to ask you about your family member's daily behaviors and sleep pattern during the **PAST TWO WEEKS**.

**DAILY BEHAVIORS (PAST TWO WEEKS)**

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

- 21. ...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
- 22. ...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
- 23. ...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
- 24. ...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 TWO WEEKS**

- 25. ...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
- 26. ... 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

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- 27. ... 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
- 28. ... 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
- 29. ...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)
- 30. ...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)
- 31. ... 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
- 32. ... 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
- 33. Is your family member required to wear a mask in their community?**
- a. Yes
  - b. No
- 34. How many days per week is your family member asked to wear a mask?**
- a. Never

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- b. 1-2 days
- c. 3-4 days
- d. 5-6 days
- e. Daily
- f. Not applicable (e.g., my family member does not leave the home)

**35. When asked to wear a mask, how easy is it to get your family member to wear a mask?**

- a. Very easy, my family member has no difficulty wearing a mask when requested
- b. Some challenges, but usually wears a mask when requested
- c. Often does not wear a mask when requested
- d. Never wears a mask when requested
- e. Not applicable, my family member has not been asked to wear a mask

**36. How many days per week does your family member wear a mask?**

- a. Never
- b. 1-2 days
- c. 3-4 days
- d. 5-6 days
- e. Daily

**37. Has your family member's access to social, therapeutic, or educational activities been limited because of being unable to wear a mask?**

- a. Yes
- b. No
- c. Not applicable

**BEHAVIORS AND INTERESTS (PAST TWO WEEKS)**

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

**38. ...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

**39. ...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

**40. ...engage in in other rituals or routines?**

- a. Not at all



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- b. Rarely
- c. Occasionally
- d. Often
- e. Regularly

**41. ...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

**42. ...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

**43. ...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**

**44. ...have any of the following been a significant problem in your family member's behavior (despite treatment, if treatment has occurred)? 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

- I. None of the above

**44a. For each symptom checked, follow up with:**

**During the past two 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:**

**45. ... 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

**46. ... 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

**47. ... 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:**

**48. ...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)

**49. ...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)?**

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- a. Not at all
- b. Rarely
- c. Occasionally
- d. Often
- 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 changes in services. We will ask you about just the  
PAST TWO WEEKS.**

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**50. In the past two weeks, 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 not had access and has not received this service during 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"/>

**50a.** [For each service above, if option (1) is selected]:

**Please specify how [insert service name] has been provided in the past two weeks:**

- Using telehealth (e.g., 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
- Through in-person appointments outside of the home

**50b.** [For each service above, if in question 50a option (a) is selected, then ask]:

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**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 in the past two weeks?**

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

**50c.** [For each service above, if in questions 50a 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 in the past two weeks?**

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

**51. Have there been changes in the services that your family member receives that have affected your family member in the PAST TWO WEEKS? Yes/No**

**51a. If yes, please indicate why (select all that apply).**

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	Changes are due to COVID-19 (1)	Changes are due to other reasons (e.g., summer/winter break, insurance change, change of town) (2)	No changes (My family member did not regularly receive this service before) (3)
Speech Therapy (1)			
Occupational Therapy (OT) (2)			
Physical Therapy (PT) (3)			
Applied Behavior Analysis Therapy (ABA Therapy) (4)			
Social Skills Therapy (5)			
General psychology / Counseling (6)			
Medical visits (e.g. Psychiatry / Developmental Pediatrics / Neurology etc.) (7)			
Recreational therapy (8)			
Vocational Support (9)			

**52. In the past two weeks, has your family member needed to access any of the following providers 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"/>

52a. Please tell us more about what you find helpful / not helpful about telehealth services, if your family member has received them: \_\_\_\_\_[TEXT BOX]

53. In the past two weeks, have there been changes in the access to the above providers? Yes/No

53a. If yes, please indicate why (select all that apply).

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	Changes are due to COVID-19 (1)	Changes are due to other reasons (e.g. summer/winter break, insurance change, change of town) (2)	No changes (My family member did not regularly receive this service before) (3)
Family Doctor / General Pediatrician (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatry (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurology / Developmental Pediatrician (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastroenterology (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychology (5)	<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"/>

**54. In the past two weeks, what of the following have you experienced overall?**

**Please select all that apply.**

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

i. None of the above



**55. In the past two weeks, have there been any changes in medications prescribed for your family member's *mental health or behavior* concerns? (Yes/No)**

**If Yes:**

**55a. 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. Not applicable, as medications were discontinued
6. Other (Please specify)
7. None of the above

**56. In the past two weeks, have there been any changes in medications prescribed for your family member's *physical health*? (Yes/No)**

**If Yes:**

**56a. 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. Not applicable, as medications were discontinued
6. Other (Please specify)
7. None of the above

#### **GENERAL IMPACT**

**57. 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.

#### **ADDITIONAL CONCERNS AND COMMENTS**

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

The CoRoNaVirus Health Impact Survey (CRISIS) Adapted For Autism and Related  
Neurodevelopmental conditions (AFAR) V0.6.1: Parent/Caregiver/Informant Follow-Up Form  
(21+ years)

[TEXT BOX]

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

[TEXT BOX]