

**The CoRonaviruS Health Impact Survey (CRISIS) - Adapted for Autism and Related
Neurodevelopmental conditions (AFAR)**
Parent/Caregiver Follow-Up Current Form V 0.5.1
(3-21 years)

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Development team for core CRISIS Survey:

The core 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 Forms (3-21 years):

The CRISIS AFAR adaptation of the baseline and follow up forms aim to assess the specific needs and changes related to the Coronavirus/COVID-19 crisis in children and adolescents (3-21 years) with autism and related neurodevelopmental conditions. The general structure of the core CRISIS forms was maintained, items focusing on relevant services, adaptive key behaviors, as well as associated symptoms were added, a few original items, not considered specific were removed, others reworded (a detailed summary of changes is available upon request to 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 CRISIS AFAR (merikank@mail.nih.gov and Adriana.DiMartino@childmind.org, respectively) though this is not required. 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) V0.5.1: Parent Caregiver Follow-Up Form

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 [ID1]: 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. -ADM

Country:

State/Province/Region:

Your age (years):

Your child's age (years):

BACKGROUND:

What is your relationship to the child?

- a. Mother
- b. Father
- c. Grandparent
- d. Aunt/Uncle
- e. Foster Parent
- f. Other: Specify _____

UPDATED CORONAVIRUS/COVID-19 HEALTH/EXPOSURE STATUS

During the PAST TWO WEEKS:

1. ... has your child 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

2. ... has your child 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

3. ... has your child 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

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

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

5. ... have any of the following happened to your child's family members 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 child been about:

6. being infected?

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

7. ... friends or family being infected?

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

8. ... his/her *Physical health* being influenced by Coronavirus/COVID-19?

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

9. ... his/her *Mental/Emotional health* being influenced by Coronavirus/COVID-19?

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

10. How much is your child 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 child's limited communication

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

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

- If answered b or c to question 11 please specify: _____

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

During the PAST TWO WEEKS:

12. ... how much time has your child 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

13. ... how stressful have the restrictions on leaving home been for your child?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely
- f. No ongoing restrictions

14. ...how much has cancellation of important events (such as birthday parties, graduation, prom, vacation, etc.) in your child's life been difficult for him/her?

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

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

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

16. ... to what degree is your child concerned about the stability of your living situation?

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

17. ... to what degree is your child worried whether your 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 child's limited communication

18. ...how hopeful is your child 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 child's limited communication

Thank you! Now we would like to ask you about your child'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 child:

- 19. ...play and/or 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
- 20. ...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
- 21. ...complete self-care activities (e.g., got dressed/changed independently/ brushed teeth/bathe/shower daily) and/or starting 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
- 22. ...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**:

- 23. ...on average, what time did your child go to bed on WEEKDAYS?**
- a. Before 8 pm
 - b. 8 pm-10 pm
 - c. 10 pm-12 am
 - d. After midnight
- 24. ... on average, what time did your child go to bed on WEEKENDS?**
- a. Before 8 pm
 - b. 8 pm-10 pm
 - c. 10 pm-12 am
 - d. After midnight
- 25. ... on average, how many hours per night did your child sleep on WEEKDAYS?**
- a. <6 hours
 - b. 6-8 hours
 - c. 8-10 hours

d. >10 hours

26. ... on average, how many hours per night did your child sleep on WEEKENDS?

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

27. ...on average, did your child 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)

28. ...on average, did your child 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)

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

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

30. ... how many days per week did your child 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 child:

31. ...engage in repetitive motor mannerisms (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

32. ...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

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

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

34. ...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

35. ...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 child)?

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

36. ...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,

37. have any of the following been a significant problem in your child'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

The CoRonaVirus Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

- f. Deliberately injuring self
- g. Being disobedient and arguing often
- h. Crying easily
- i. Being excessively worried about social situations (e.g. going to school, attending birthday parties, speaking publicly)
- j. Being excessively worried on separating from parent/ caregiver
- k. Seeming excessively fearful
- l. None of the above

37a. For each symptom checked, follow up with:

During the past two weeks how much of a problem has this been for you?

- 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 child spend:

38. ... 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

39. ... 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

Commented [ID2]: Skip < age 5 years

40. ... 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 child...

41. ...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

Commented [ID3]: Skip < age 5 years

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

42. ...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)

Commented [ID4]: Skip < age 5 years

SCHOOL and SERVICES

Thank you for answering the questions above.

Now we would like to ask you about changes in services in school and from outside providers. We will ask you about just the PAST TWO WEEKS.

43. In the past two weeks, how has your child's access to the following interventions or services IN SCHOOL been affected? Skip if your child is on a regular summer/winter school break

	My child continues to receive this service through their school (may be modified) (1)	My child has not had access and has not received this service since COVID-19 (2)	My child did not regularly receive this service before (3)
Academic/functional skills education(1)			
Speech Therapy (2)			
Occupational Therapy (OT) (3)			
Physical Therapy (PT) (4)			
Applied Behavior Analysis Therapy (ABA Therapy) (5)			
Social Skills Therapy (6)			
General psychology/ in-school counseling (7)			

43b. *[For each service above, if option (1) is selected, then ask]: Please Specify how [insert service name from above] has been provided in the past 2 weeks:*

- a. Using telehealth (Zoom, skype, phone conversations)
- b. Through emails and materials sent to my home
- c. By a teacher, behaviorist, or therapist coming to my home
- d. Through in-person appointments outside of the home

43c. *[For each service above, if in question 43b option (a) is selected, then ask]:*

Please for the [specify the service depending on prior answer with if logic] that your child is now receiving via telehealth (e.g., Zoom, Skype, phone conversations) how helpful have you found these accommodations in the past 2 weeks?

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

43d. *[For each service above, if in question 43b option (b) is selected, then ask]:*

Please for the [specify the service depending on prior answer with if logic] that your child is now receiving via emails or materials sent to your home:

how helpful have you found these accommodations in the past 2 weeks?

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

44. Have there been changes in the services that your child receives THROUGH THE SCHOOL that have affected your child in the PAST TWO WEEKS? Y/N

44a. If yes, Please indicate why (select all that apply)..

The CoRonavIruS Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

	Changes are due to COVID-19 (1)	Changes are due to other reasons (e.g., summer break, new school year, change of town) (2)	No Changes (My child did not regularly receive this service before) (3)
Academic/functional skills education (1)			
Speech Therapy (2)			
Occupational Therapy (OT) (3)			
Physical Therapy (PT) (4)			
Applied Behavior Analysis Therapy (ABA Therapy) (5)			
Social Skills Therapy (6)			
General psychology/ in-school counseling (7)			

45. In the past 2 weeks, how has your access to the following interventions or services that your child receives OUTSIDE OF SCHOOL been affected by the coronavirus (COVID-19) outbreak?

The CoRoNaViruS Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

	My child continues to receive this service (may be modified) (1)	My child has not had access and has not received this service COVID-19 (2)	My child 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: (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"/>

45b. [For each service above, if option (1) is selected, then ask]: **Please Specify how [insert service name] has been provided in the past 2 weeks:**

- Using telehealth (Zoom, skype, phone conversations)
- Through emails and materials sent to my home
- By a teacher, behaviorist, or therapist coming to my home
- Through in-person appointments outside of the home

45c. [For each service above, if in question 45b option (a) is selected, then ask]:

Please for the [specify the service depending on prior answer with if logic] that your child is now receiving via telehealth (e.g., Zoom, Skype, phone conversations) how helpful have you found these accommodations in the past 2 weeks?

- Not helpful at all
- A little helpful
- Somewhat helpful
- Extremely helpful

45d. [For each service above, if in questions 45b option (b) is selected, then ask]:

Please for the [specify the service depending on prior answer with if logic] that your child is now receiving via emails or materials sent to my home:

how helpful have you found these accommodations in the past 2 weeks?

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

46. Have there been changes in the services that your child receives OUTSIDE SCHOOL that have affected your child in the PAST TWO WEEKS? Y/N

46a. If yes please indicate why (select all that apply).

The CoRonaVirus Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

	Changes are due to COVID-19 (1)	Changes are due to other reasons (e.g. summer break, insurance change, change of town) (2)	No Changes (My child 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 (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"/>

47. In the past two weeks, has your child needed to access any of the following providers and how did they do so?

The CoRonaVirus Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

	My child has not needed access to this type of provider (1)	Yes, my child has accessed through telehealth or telemedicine (2)	Yes, my child has accessed through at-home appointments (3)	Yes, my child has accessed through in-person office appointments (4)	My child 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 (e.g., endocrinology, dentistry) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

48. In the past two weeks have there have been changes in the access to the above providers? Y/N

48a. If yes, Please indicate why (select all that apply).

The CoRonaVirus Health Impact Survey (CRISIS) V0.5.1: Parent Caregiver Follow-Up Form

	Changes are due to COVID-19 (1)	Changes are due to other reasons (e.g. summer break, insurance change, change of town) (2)	No Changes (My child 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 Pediatrics (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 (e.g., endocrinology, dentistry) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

49. In the past two weeks, what of the following have you experienced overall? Please select all that apply.

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

50. In the past 2 weeks, have there been any changes in any medications prescribed for your child's *mental health or behavior* concern?(Y/N)

If Yes:

50 a. Which options would be the most helpful to best manage your child's medications?

- 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. Medications were discontinued
- 6. Other (Please specify)
- 7. None of the above

51. In the past 2 weeks, have there been any changes in medication prescribed for your child's *physical health*? (Y?N)

If Yes:

51 a. Which options would be the most helpful to best manage your child's medications?

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. Medications were discontinued.
6. Other (Please specify)

ADDITIONAL CONCERNS AND COMMENTS

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

[TEXT BOX]

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

[TEXT BOX]