# The CoRonavIruS Health Impact Survey (CRISIS) - Adapted for Autism and Related Neurodevelopmental conditions (AFAR)- V0.5.1

Parent/Caregiver Baseline Form (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.

Content contributors and consultants included: Evelyn Bromet, Stan Colcombe, Kathy Georgiades, Dan Klein, Giovanni Salum

Coordinators: Lindsay Alexander, Ioanna Douka, Julia Dunn, Diana Lopez, Ken Towbin

Technical and editing support: Irene Droney, Beth Foote, Jianping He, Georgia O' Callaghan, Judith Milham, Courtney Quick, Diana Paksarian, Kayla Sirois

#### Development team for the CRISIS AFAR Survey:

The adaptation was aimed 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. Briefly, the general structure of the core CRISIS forms was maintained, items focusing on services, adaptive key behaviors, as well as associated symptoms relevant for ASD 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 <a href="Adriana.DiMartino@chidmind.org">Adriana.DiMartino@chidmind.org</a>).

Content Developers: Adriana Di Martino, Louise Gallagher, Stelios Georgiades, Panagiota (Neny) Pervanidou, Audrey Thurm, Bethany Vibert. Additional Content: the section entitled School and Services was based largely on questions selected from the CARING through COVID questionnaire developed by Shafali Jeste and her colleagues and slightly adapted.

Consultants: So Hyun (Sophy) Kim, Meng-Chuan Lai

Editing and Technical Support: Evdokia Anaganostu, Lindsay Alexander, Jacob Stroud, Irene Droney

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

Identification Number:

Country.	
State/Provid	ence/Region:
Your age (ye	ears):
Your child's	age (years):
BACKGROU	ND:
	we get started with the main questions, we would like to collect round information about your child and family.
1. What	is your relationship to the child?
a.	Mother
b.	Father
C.	Grandparent
	Aunt/Uncle
	Foster Parent
f.	Other: Specify
2. Pleas	e specify your child's sex at birth:
a.	Male
	Female
C.	Other
	e specify your child's gender:
	Boy/Man
	Girl/Woman
	Trans boy / Trans man
	Trans girl / Trans woman
	Non-binary
f.	Identity not listed (please specify:)
follow ances	ing about what you know of your child's family history, which of the ring best describes the geographic regions from where your child's tors (i.e. great-great-grandparents) came from? You may select as choices as needed.
	England, Ireland, Scotland or Wales
	Australia – not of Aboriginal or Torres Strait Islander descent

c. Australia - of Aboriginal or Torres Strait Islander descent

f. Northern Europe including Sweden, Norway, Finland and surrounding

d. New Zealand – not of Maori descente. New Zealand – of Maori descent

countries

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

- g. Western Europe including France, Germany, the Netherlands and surrounding countries
- h. Eastern Europe, including Russia, Poland, Hungary and surrounding countries
- 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
- I. 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 child 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. Is your child enrolled in school/college for the current academic year?
  - a. Not in school
  - b. Preschool/Kindergarten
  - c. Elementary school
  - d. Junior High or Middle School
  - e. High School
  - f. College(University)/Vocational
  - g. Graduate school
- 7. Which best describes the area in which your child lives?
  - a. Large city
  - b. Suburbs of a large city
  - c. Small city
  - d. Town or village
  - e. Rural area
- 8. What is the highest level of education YOU completed?
  - a. Some grade school

- b. Some high school
- c. High school diploma or GED
- 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

### 9. What is the highest level of education your child's second parent/caregiver completed?

- a. Some grade school
- b. Some high school
- c. High school diploma or GED
- 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

### 10. Which of the following applied to your child's educational setting <u>BEFORE</u> the Coronavirus (COVID-19) crisis in your area:

- a. My child attended a general education school program (i.e. "regular" classroom) with support or services (e.g., classroom aide, resource room, modified activities).
- b. My child attended a special education school program (i.e., special education classroom) within a public-school district.
- My child attended a special education school program at a private or nonpublic school.
- d. My child attended a center-based program (i.e., ABA center).
- e. My child attended a home-based program (i.e., homeschooled by parent, home-based ABA program).
- f. My child was in a residential placement and did not live at home.
- g. My child attended a general education school program without any individualized educational services

11.	How many people currently	live in your	child's home	(excluding you	ır
	child)?				

#### 12. Please specify their relationship(s) to your child (check all that apply):

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

13. Are any adults living in the home an ESSENTIAL WORKER (e.g., healthcare, delivery worker, store worker, security, building
maintenance)? (Y/N)
a. If yes,
Do they come home each day?     Yes
<ul> <li>No, separated due to COVID-19</li> </ul>
<ul> <li>No separated due to other reasons</li> </ul>
<ul> <li>Are they a FIRST RESPONDER, HEALTHCARE PROVIDER of OTHER WORKER in a facility treating COVID-19? (Y/N)</li> </ul>
14. How many rooms (total) are in your child's home?
15.Is your child 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
16. 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? <ul> <li>a. Yes</li> <li>b. No</li> </ul>
17. How tall is your child? centimeters(cm)/inches(in)
18. How much does your child weigh? kilograms(kg)/pounds(lbs)
19. How would you rate your child's overall physical health?  a. Excellent
b. Very Good c. Good
d. Fair
e. Poor
20. Has a health or educational professional ever told you that your child 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
a. Maney 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
- I. Serious acne or skin problems
- m. Vision problems
- n. Hearing problems
- 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

20a. If you checked any between v and y, [insert] please specify\_\_\_\_\_\_

20b. [If one or more of the response options between r and x on question 20 were selected, then ask]: How much language did your child spontaneously use on a daily basis for 1 month consistently prior to the COVID-19 crisis in your area?

- a. No words/does not speak
- b. Uses single words meaningfully (for example, to request)
- c. Combines three words together into short sentences
- 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:

# 21.... 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

### 22.... has your child been suspected of having Coronavirus/COVID-19 infection?

- a. Yes, has 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

#### 23.... 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

## 24.... 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

# 25.... have any of the following happened to your child's family members because of Coronavirus/COVID-19 pandemia? (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:

#### 26.... being infected?

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

#### 27.... friends or family being infected?

- a. Not at all
- b. Slightly

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

#### 28.... his/her Physical health being influenced by Coronavirus/COVID-19?

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

#### 29.... his/her Mental/Emotional health being influenced by Coronavirus/COVID-

19?

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

## 30. 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

# 31. 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 31, please specify: \_\_\_\_\_

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

#### During the PAST TWO WEEKS:

- 32.... 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
- 33.... how stressful have the restrictions on leaving home been for your child?
  - a. Not at all / no changes
  - b. Slightly
  - c. Moderately
  - d. Very
  - e. Extremely
- 34. ...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
- 35.... 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
- 36.... to what degree your 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
- 37.... 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

### 38....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 for completing the questions above.

In order to better assess the COVID-19 crisis impact on your child, we would first like to ask about your child's daily behaviors and sleep during the <a href="https://doi.org/10.108/jwise-10.108-jwis

#### DAILY BEHAVIORS (THREE MONTHS PRIOR TO CRISIS)

During the <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area how independently did your child...

#### 39.... 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

# 40....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

# 41....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

# 42....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 <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area

#### 43.... 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

#### 44.... 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

## 45.... 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

## 46.... 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

# 47....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)

# 48....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)

- 49.... how many days per week did your child 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
- 50.... 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 (THREE MONTHS PRIOR TO CRISIS)

During the <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area, how frequently did your child:

- 51....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
- 52....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
- 53....engage in other rituals or routines?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly

- 54....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
- 55....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
- 56....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 <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area

- 57.... 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
  - f. Deliberately injuring self
  - g. Being disobedient and arguing often
  - h. Crying easily
  - 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
- I. None of the above

# 57a. For each symptom checked, follow up with: How much of a problem has this been for you?

m. Slightly

n. Moderately

o. Very Much

p. A lot

#### MEDIA USE (THREE MONTHS PRIOR TO CRISIS)

During the <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area, how much time per day did your child spend:

#### 58.... 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

### 59.... 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

#### 60.... 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 <u>THREE MONTHS PRIOR</u> to the onset of the Coronavirus/COVID-19 crisis in your area, how frequently did your child:

# 61....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

Commented [ADM2]: Skip < age 5 years

Commented [ADM3]: Skip < age 5 years

- e. Regularly
- f. Not Applicable (e.g., no opportunity)
- 62...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 child's daily behaviors and sleep during the <u>PAST TWO WEEKS</u>.

#### **DAILY BEHAVIORS (PAST TWO WEEKS)**

During the PAST TWO WEEKS, how independently did your child:

- 63....play and/or entertain self appropriately for at least 20 minutes?
  - e. Independently (without support, prompting, or supervision)
  - f. With moderate supervision (some verbal and/or visual reminders)
  - g. With close supervision (support including step-by-step instruction)
  - h. Not at all
- 64....structure/initiate daily activities (e.g., started and completed schoolwork/homework/chores, followed general schedule of completing activities)?
  - e. Independently (without support, prompting, or supervision)
  - f. With moderate supervision (some verbal and/or visual reminders)
  - g. With close supervision (support including step-by-step instruction)
  - h. Not at all
- 65....complete self-care activities (e.g., got dressed/changed independently/brushed teeth/bathe/shower daily) and/or starting day's activities?
  - e. Independently (without support, prompting, or supervision)
  - f. With moderate supervision (some verbal and/or visual reminders)
  - g. With close supervision (support including step-by-step instruction)
  - h. Not at all
- 66....manage mealtime and food related needs (e.g., preparing, organizing, and cleaning up)?
  - e. Independently (without support, prompting, or supervision)
  - f. With moderate supervision (some verbal and/or visual reminders)

Commented [ADM4]: Skip < 5 years of age

- g. With close supervision (support including step-by-step instruction)
- h. Not at all

#### **DURING THE PAST 2 WEEKS**

#### 67....on average, what time did your child go to bed on WEEKDAYS?

- e. Before 8 pm
- f. 8 pm-10 pm
- g. 10 pm-12 am
- h. After midnight

#### 68.... on average, what time did your child go to bed on WEEKENDS?

- e. Before 8 pm
- f. 8 pm-10 pm
- g. 10 pm-12 am
- h. After midnight

### 69.... 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

### 70.... 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

# 71....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)

# 72....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)

- 73.... how many days per week did your child 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
- 74.... 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:

- 75....engage in repetitive motor mannerisms/movements (e.g., repetitive movements of the whole body, or just with their hands and fingers)?
  - f. Not at all
  - g. Rarely
  - h. Occasionally
  - i. Often
  - j. Regularly
- 76....engage in sensory seeking behaviors (e.g., visually inspecting things, touching or feeling things for a long time)?
  - f. Not at all
  - g. Rarely
  - h. Occasionally
  - i. Often
  - j. Regularly
- 77....engage in in other rituals or routines?
  - f. Not at all
  - g. Rarely
  - h. Occasionally
  - i. Often
  - j. Regularly
- 78....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
- 79....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)?
  - f. Not at all
  - g. Rarely
  - h. Occasionally
  - i. Often
  - j. Regularly
- 80....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**

- 81....have any of the following been a <u>significant</u> problem in your child's behavior (despite treatment, if treatment has occurred) )? Please check all that apply:
  - a. Hyperactivity
  - b. Difficulty staving 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. Being disobedient and arguing often
  - h. Crying easily
  - 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
  - I. None of the above
  - 86a. For each symptom checked, follow up with: During the past 2 weeks how much of a problem has this been for you?

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- 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:

- 82.... 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
- 83. ... 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
- 84.... playing video games?
  - f. No video games
  - g. Under 1 hour
  - h. 1-3 hours
  - i. 4-6 hours
  - j. More than 6 hours

#### During the PAST TWO WEEKS how frequently did your child:

- 85....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)
- 86. ...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

Commented [ID5]: Skip < age 5 years

Commented [ID6]: Skip < age 5 years

Commented [ID7]: Skip < age 5 years

- b. Rarelyc. Occasionallyd. Oftene. Regularlyf. Not Applicable (e.g., no opportunity)

#### **SCHOOL and SERVICES**

Thank you for answering the questions above.

Now we would like to ask you about services in school and from outside providers that may have been affected since the Coronavirus/COVID-19 crisis in your area.

- 87. How have your child's educational and other services been affected SINCE the Coronavirus (COVID-19) crisis in your area began? Please select all that apply.
  - a. My child has had to continue his/her education at home.
  - b. My child has moved back home from a residential care facility.
  - c. My child's school is closed.
  - d. My child's residential facility is closed to visitors.
  - e. My child has lost access to some education, interventions, services, or healthcare.
  - f. My child's education and access to therapy has not been impacted due to Coronavirus (COVID-19).

# 88. How has your child's access to the following interventions or services that your child receives IN SCHOOL been affected by the Coronavirus (COVID-19) crisis?

19) Crisis?			
	My child continues to receive this service through their school (may be modified) (1)	My child has lost 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/ inschool counseling (7)			

#### 88a. For each service above, if option (1) is selected:

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

- 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

88b. [For each service above, if in question 88a option (a) is selected, then ask]:
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?

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

**88c.** [For each service above, if in question 88a 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 home:

how helpful have you found these accommodations?

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

# 89. How has your access to the following interventions or services that your child receives OUTSIDE OF SCHOOL been affected by the Coronavirus (COVID-19) crisis?

	My child continues to receive this service (may be modified) (1)	My child has lost access and has not received this service since COVID-19 (2)	My child did not regularly receive this service before (3)
Speech Therapy (1)	0	$\circ$	$\circ$
Occupational Therapy (OT) (2)	0	0	$\circ$
Physical Therapy (PT) (3)	0	$\circ$	$\circ$
Applied Behavior Analysis Therapy (ABA Therapy) (4)	0	$\circ$	0
Social Skills Therapy (5)	0	$\circ$	$\circ$
General psychology/ counseling (6)	0	$\circ$	$\circ$
Medical visits (Psychiatry/Developmental Pediatrics /Neurology etc.) (7)	0	0	0
Recreational Therapy (8)	0	$\circ$	$\circ$

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

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

- 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

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 child 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 child 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 child needed to access any of the following providers since the Coronavirus (COVID-19) outbreak and how did they do so?

	My child has not needed access to this type of provider	Yes, my child has accessed through telehealth or telemedicine	Yes, my child has accessed through at- home appointments	Yes, my child has accessed through in- person office appointments	My child could not access this provider
Family Doctor/ General Pediatrician (1)	0	0	0	0	0
Psychiatry (2)	0	$\circ$	$\circ$	$\circ$	$\circ$
Neurology/Developmental Pediatrician (3)	0	$\circ$	0	0	0
Gastroenterology (4)	0	$\circ$	0	0	$\circ$
Psychology (5)	0	$\circ$	$\circ$	$\circ$	$\circ$
Other subspecialties (such as endocrinology, dentistry) (6)	0	$\circ$	$\circ$	$\circ$	0

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

- a. My child's routine appointments have been canceled or postponed.
- 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).
- 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)
- i. None of the above

## 92. Is your child prescribed any medications for *mental health or behavior* concerns?(Y/N)

a. If Yes:

# 92a. Which options would be the most helpful to best manage your child's medications? (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 child prescribed any other medications for physical health? (Y/N)

a. If Yes:

# 93a. Which options would be the most helpful to best manage your child's medications? (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

#### **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 to share about this survey and/or related topics.

[TEXT BOX]