## The CoRonavIruS Health Impact Survey (CRISIS) Adapted For Autism and Related neurodevelopmental conditions (AFAR) V0.5.1

Adult and Youth Self-Report Baseline Form

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

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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 adolescents and adults (>14 years) 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 <a href="mailto:Adriana.DiMartino@chidmind.org">Adriana.DiMartino@chidmind.org</a>).

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@childmind.org if you would like to make de-identified data contributions for the CRISIS AFAR

Identification Number:	 	
Country:		
State/Providence/Region:		
Your age (years):		
BACKGROUND		

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

First, before we get started with the main questions, we would like to obtain some background information about you.

- 1. Please specify your sex at birth:
  - a. Male
  - b. Female
  - c. Other\_
- 2. Please specify your gender:
  - a. Boy / Man
  - b. Girl / Woman
  - c. Trans boy / Trans man
  - d. Trans girl / Trans woman
  - e. Non-binary
  - f. Identity not listed (please specify: \_\_\_\_\_)
- 3. Thinking about what you know of your family history, which of the following best describes the geographic regions from where your ancestors (e.g. your greatgreat-grandparents) came? You may select as many choices as you need.
  - 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
  - Southern Europe including Italy, Greece, Spain, Portugal and surrounding
  - 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

  - 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
- 4. Are you 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
- 5. Are you currently working or in school?
  - a. Working for pay
  - b. On leave
  - c. Laid off or lost job
  - d. Unemployed and looking for a job
  - e. Retired
  - f. Staying at home / homemaker
  - g. Disabled
  - h. Enrolled in school/college/university
- 6. If you are working, what is your occupation? \_\_\_\_\_
- 7. If you are currently enrolled in school/college for the current academic year, are you enrolled in:
  - a. Not in school
  - b. Elementary school
  - c. Junior High or Middle School
  - d. High School
  - e. College, University or Vocational School (including technical or trade school)
  - f. Graduate School
- 8. Have you served in the military?
  - a. Yes
  - b. No
- 9. Which best describes the area in which you live?
  - a. Large city
  - b. Suburbs of a large city
  - c. Small city
  - d. Town or village
  - e. Rural area
- 10. 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

11. How many people currently live in your home (excluding yourself)? \_\_\_\_

12. Please specify your relationship to the people in your home (check all that apply):  a. Partner/Spouse b. Parent(s) c. Grandparent(s) d. Siblings e. 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)? 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
14. How many rooms (total) are in your home?
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?  a. Yes b. No
17. How would you rate your overall physical health before the Coronavirus/COVID-19 crisis in your area?  a. Excellent b. Very Good c. Good d. Fair e. Poor
18. How would you rate your overall mental/emotional health before the Coronavirus/COVID-19 crisis in your area?

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- a. Excellent
- b. Very Good
- c. Good
- d. Fair
- e. Poor
- 19. Has a health or educational professional ever told you that you 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
  - 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

19a. If	vou checked any	between v and y	. [insert] please	specify
ı Ja. II	you chocked and	y botwoon v and y	, princerti picasc	SPCCII y

- 20. How tall are you? \_\_\_ centimeters(cm)/inches(in)
- 21. How much do you weigh? \_\_\_ kilograms(kg)/pounds(lbs)

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

#### **During the PAST TWO WEEKS:**

- 22. ... have you 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

## 23. ... have you been suspected of having Coronavirus/COVID-19 infection?

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

### 24. ... have you 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

## 25. ... has anyone in your family been diagnosed with Coronavirus/COVID-19? (check all that apply)

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

## 26. ... have any of the following happened to your 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 have you been about:

### 27. .... being infected by Coronavirus / having COVID-19?

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

## 28. ... your friends or family being infected by Coronavirus / having COVID-19?

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

29 v	our ph	vsical	health t	peina	influenced	bv	Coronavirus	s/COVID-	19?

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

### 30. ... your mental/emotional health being influenced by Coronavirus/COVID-19?

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

## 31. How much are you reading, watching content, or talking about Coronavirus/COVID-19?

- a. Never
- b. Rarely
- c. Occasionally
- d. Often
- e. Most of the time

## 32. Has the Coronavirus/COVID-19 crisis in your area led to any positive changes in your life?

- a. None
- b. Only a few
- c. Some
- If answered b or c to question 32, please specify what these positive changes are: \_\_\_\_

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

### **During the PAST TWO WEEKS:**

## 33. ... if you attend school, has your school building been closed? Yes/No/Not Applicable

- a. **If no**,
  - Are classes in session? Yes/No
  - Are you attending classes in-person? Yes/No
- b. If yes,
  - Have classes resumed online? Yes/No
  - Do you have easy access to the internet and a computer? Yes/No
  - Are there assignments for you to complete? Yes/No
  - Are you able to receive meals from the school? Yes/No

Did you lose your job? Yes/No

34 if you ha Yes/No/Not	d a job prior to the Coronavirus/COVID-19 crisis, are you still working? Applicable
a. If ye	5,
•	Are you still going to your workplace? Yes/No
•	Are you teleworking or working from home? Yes/No
b. <b>If no</b>	,
•	Were you laid off from your job? Yes/No

- 35. ... how many people, from outside of your household, have you had an in-person conversation with? \_\_\_\_
- 36. ... how much time have you 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
- 37. ... how stressful have the restrictions on leaving home been for you?
  - a. Not at all / no changes
  - b. Slightly
  - c. Moderately
  - d. Very
  - e. Extremely
- 38. ... have your contacts (in any format) with people outside of your home changed relative to *before* the Coronavirus/COVID-19 crisis in your area?
  - a. A lot less
  - b. A little less
  - c. About the same
  - d. A little more
  - e. A lot more
- 39. ... how much difficulty have you had following the recommendations for keeping away from close contact with people (i.e., "physical distancing", staying away from other people by the recommended physical distance)?
  - a. None
  - b. A little
  - c. Moderate
  - d. A lot
  - e. A great amount
- 40. ... has the quality of the relationships between you and members of your family changed?
  - a. A lot worse
  - b. A little worse
  - c. About the same

- d. A little better
- e. A lot better

#### 41. ... how stressful have these changes in family contacts been for you?

- a. Not at all / no changes
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

### 42. ... has the quality of your relationships with your friends changed?

- a. A lot worse
- b. A little worse
- c. About the same
- d. A little better
- e. A lot better

### 43. ... how stressful have these changes in social contacts been for you?

- a. Not at all / no changes
- b. Slightly
- c. Moderately
- d. Very
- e. Extremely

#### 44. ...has cancellation of important events (such as graduation, prom, vacation, etc.) in your life been difficult for you?

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

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

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

#### 46. ... to what degree are you concerned about the stability of your living situation?

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

## 47. ... did you worry whether your food would run out because of a lack of money? a. Yes

- b. No

- 48. How hopeful are you that the Coronavirus/COVID-19 crisis in your area will end soon?
  - a. Not at all
  - b. Slightly
  - c. Moderately
  - d. Very
  - e. Extremely

Thank you for completing the questions above.

In order to better assess the COVID-19 crisis impact, we would first like to ask about your daily behaviors and sleep during the <u>THREE MONTHS PRIOR</u> 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  $\underline{\mathsf{THREE}}$   $\underline{\mathsf{MONTHS}}$   $\underline{\mathsf{PRIOR}}$  to the onset of the Coronavirus/COVID-19 crisis in your area:

- 49. ... on average, what time did you go to bed on WEEKDAYS?
  - a. Before 9 pm
  - b. 9 pm-11 pm
  - c. 11 pm-1 am
  - d. After 1 am
- 50. ... on average, what time did you go to bed on WEEKENDS?
  - a. Before 9 pm
  - b. 9 pm-11 pm
  - c. 11 pm-1 am
  - d. After 1 am
- 51. ... on average, how many hours per night did you sleep on WEEKDAYS?
  - a. <6 hours
  - b. 6-8 hours
  - c. 8-10 hours
  - d. >10 hours
- 52. ... on average, how many hours per night did you sleep on WEEKENDS?
  - a. <6 hours
  - b. 6-8 hours
  - c. 8-10 hours
  - d. >10 hours
- 53. ...on average, did you 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)
- 54. ...on average, did you 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)
- 55. ... how many days per week did you 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
- 56. ... how many days per week did you 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 you:

- 57. ...engage in repetitive motor mannerisms/movement (e.g., repetitive movements of the whole body, or hands and fingers, such as hand flapping, finger flicking)?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly
- 58. ...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
- 59. ...engage in other rituals or routines?
  - a. Not at all
  - b. Rarely
  - c. Occasionally

- d. Often
- e. Regularly
- 60. ...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
- 61. ...require family members and others that you interact with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly
- 62. ...engage in an activity related to a highly specific and strong interest (e.g., play with the object/topic, talk about the object/topic, watch content related to that object/topic)?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly

## **EMOTIONS/WORRIES (THREE MONTHS PRIOR TO CRISIS)**

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

- 63. ... how worried were you generally?
  - a. Not worried at all
  - b. Slightly worried
  - c. Moderately worried
  - d. Very worried
  - e. Extremely worried
- 64. ... how happy versus sad were you?
  - a. Very sad/depressed/unhappy
  - b. Moderately sad/depressed/unhappy
  - c. Neutral
  - d. Moderately happy/cheerful
  - e. Very happy/cheerful
- 65. ... how much were you able to enjoy your usual activities?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very much
- e. A lot

### 66. ... how relaxed versus anxious were you?

- a. Very relaxed/calm
- b. Moderately relaxed/calm
- c. Neutral
- d. Moderately nervous/anxious
- e. Very nervous/anxious

## 67. ... how fidgety or restless were you?

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

#### 68. ... how fatigued or tired were you?

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

### 69. ... how well were you able to concentrate or focus?

- a. Very focused/attentive
- b. Moderately focused/attentive
- c. Neutral
- d. Moderately unfocused/distracted
- e. Very unfocused/distracted

### 70. ... how irritable or easily angered were you?

- a. Not irritable or easily angered at all
- b. Slightly irritable or easily angered
- c. Moderately irritable or easily angered
- d. Very irritable or easily angered
- e. Extremely irritable or easily angered

## 71. ... how lonely were you? a. Not lonely at all

- b. Slightly lonely
- c. Moderately lonely
- d. Very lonely
- e. Extremely lonely

### 72. ... to what extent did you have negative thoughts, thoughts about unpleasant experiences or things that made you feel bad?

a. Not at all

- b. Rarely
- c. Occasionally
- d. Often
- e. A lot of the time
- 73. ... to what extent did you have support from other people to make important decisions or to help you deal with problems?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. A lot of the time

## 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 you spend:

- 74. ... 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
- 75. ... 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
- 76. ... playing video games?
  - a. No video games
  - b. Under 1 hour
  - c. 1-3 hours
  - d. 4-6 hours
  - e. More than 6 hours

## SUBSTANCE 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 frequently did you use:

- 77. ... alcohol?
  - a. Not at all
  - b. Rarely
  - c. Once a month

- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 78. ... vaping products?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 79. ... cigarettes or other tobacco products?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 80. ... marijuana/cannabis (e.g., joint, blunt, pipe, bong)?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

### 81. ... opiates, heroin, or narcotics?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 82. ... other drugs including cocaine, crack, amphetamine, methamphetamine, hallucinogens, or ecstasy?

- a. Not at all
- b. Rarely
- c. Once a month

- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 83. ... sedatives or hypnotics?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

Thank you for answering the questions above.

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

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

### During the PAST TWO WEEKS:

- 84. ... on average, what time did you go to bed on WEEKDAYS?
  - a. Before 9 pm
  - b. 9 pm-11 pm
  - c. 11 pm-1 am
  - d. After 1 am
- 85. ... on average, what time did you go to bed on WEEKENDS?
  - a. Before 9 pm
  - b. 9 pm-11 pm
  - c. 11 pm-1 am
  - d. After 1 am
- 86. ... on average, how many hours per night did you sleep on WEEKDAYS?
  - a. <6 hours
  - b. 6-8 hours
  - c. 8-10 hours
  - d. >10 hours
- 87. ... on average, how many hours per night did you sleep on WEEKENDS?
  - a. <6 hours
  - b. 6-8 hours
  - c. 8-10 hours
  - d. >10 hours

- 88. ...on average, did you 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)
- 89. ... on average, did you 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)
- 90. ... how many days per week did you 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
- 91. ... how many days per week did you 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 you:

- 92. ...engage in repetitive motor mannerisms/movement (e.g., repetitive movements of the whole body, or hands and fingers, such as hand flapping, finger flicking)?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly
- 93. ...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

- 94. ...engage in other rituals or routines?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly
- 95. ...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
- 96. ...require family members and others that you interact with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly
- 97. ...engage in an activity related to a highly specific and strong interest (e.g., play with the object/topic, talk about the object/topic, watch content related to that object/topic)?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. Regularly

## **EMOTIONS/WORRIES (PAST TWO WEEKS)**

### During the PAST TWO WEEKS:

- 98. ... how worried were you generally?
  - a. Not worried at all
  - b. Slightly worried
  - c. Moderately worried
  - d. Very worried
  - e. Extremely worried
- 99. ... how happy versus sad were you?
  - a. Very sad/depressed/unhappy
  - b. Moderately sad/depressed/unhappy
  - c. Neutral

- d. Moderately happy/cheerful
- e. Very happy/cheerful

#### 100. ... how much were you able to enjoy your usual activities?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Very much
- e. A lot

## 101. ... how relaxed versus anxious were you?

- a. Very relaxed/calm
- b. Moderately relaxed/calm
- c. Neutral
- d. Moderately nervous/anxious
- e. Very nervous/anxious

### 102. ... how fidgety or restless were you?

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

## 103. ... how fatigued or tired were you?

- a. Not fatigued or tired at all
- b. Slightly fatigued or tired
- c. Moderately fatigued or tired
- d. Very fatiqued or tired
- e. Extremely fatigued or tired

### 104. ... how well were you able to concentrate or focus?

- a. Very focused/attentive
- b. Moderately focused/attentive
- c. Neutral
- d. Moderately unfocused/distracted
- e. Very unfocused/distracted

### 105. ... how irritable or easily angered were you?

- a. Not irritable or easily angered at all
- b. Slightly irritable or easily angered
- c. Moderately irritable or easily angered
- d. Very irritable or easily angered
- e. Extremely irritable or easily angered

### 106. ... how lonely were you?

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

- ... to what extent did you have negative thoughts, thoughts about 107. unpleasant experiences or things that make you feel bad?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - e. A lot of the time
- ... to what extent did you have support from other people to make important decisions or to help you deal with problems?
  - a. Not at all
  - b. Rarely
  - c. Occasionally
  - d. Often
  - A lot of the time

## **MEDIA USE (PAST TWO WEEKS)**

During the PAST TWO WEEKS, how much time per day did you spend:

- 109. ... watching TV or digital media (e.g., Netflix, YouTube, web surfing)?
  - a. No TV or digital media
  - b. Under 1 hour

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

## **SUBSTANCE USE (PAST TWO WEEKS)**

During the PAST TWO WEEKS, how frequently did you use:

- 112. ... alcohol?
  - a. Not at all
  - b. Rarely

- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

#### 113. ... vaping products?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

### 114. ... cigarettes or other tobacco products?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

### 115. ... marijuana/cannabis (e.g., joint, blunt, pipe, bong)?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

### 116. ... opiates, heroin, or narcotics?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 117. ... other drugs including cocaine, crack, amphetamine, methamphetamine, hallucinogens, or ecstasy?

a. Not at all

- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## 118. ... sedatives or hypnotics?

- a. Not at all
- b. Rarely
- c. Once a month
- d. Several times a month
- e. Once a week
- f. Several times a week
- g. Once a day
- h. More than once a day

## **SUPPORTS**

- 119. Which of the following supports were in place for you before the Coronavirus/COVID-19 crisis in your area and have been disrupted over the PAST TWO WEEKS? (check all that apply)
  - a. Resource room
  - b. Tutoring
  - c. Mentoring programs
  - d. After school activity programs
  - e. Volunteer programs
  - f. Psychotherapy (e.g., cognitive behavioral therapy)
  - g. Psychiatric care
  - h. Occupational therapy
  - i. Physical therapy
  - j. Speech/language therapy
  - k. Sporting activities
  - Medical care for chronic illnesses
  - m. Counseling
  - n. Social skills group
  - o. Peer support group
  - p. Vocational support (e.g., supported employment, interview training)
  - q. Other: Specify \_\_\_\_\_
  - r. None of the above

## 120. How have your educational and other services been affected SINCE the Coronavirus (COVID-19) crisis in your area began? Please select all that apply.

- a. I have had to continue my education at home.
- b. I have moved back home from a residential care facility.
- c. My school is closed.
- d. My residential facility is closed to visitors.
- e. I have lost access to some education, interventions, services, or healthcare.
- f. My education and access to therapy has not been impacted due to Coronavirus (COVID-19).

# 121. How has your access to the following interventions or services that you receive IN SCHOOL been affected by the Coronavirus (COVID-19) crisis? [Note: skip if not in school]

I continue to	I have lost access	
receive this service	and has not	I did not regularly
through my school	received this	receive this service
(may be modified)	service since	before (3)
(1)	COVID-19 (2)	

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)

### 121a. For each service above, if option (1) is selected:

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

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

121b. [For each service above, if in question 121a option (a) is selected, then ask]: for the [specify the service depending on prior answer with if logic] that you are 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

121c. [For each service above, if in question 121a option (b) is selected, then ask]: for the [specify the service depending on prior answer with if logic] that you are 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

## 122. How has your access to the following interventions or services that you receive (outside of school) been affected by the Coronavirus (COVID-19) crisis?

	I continue to receive this service (may be modified) (1)	I have lost access and has not received this service since COVID-19 (2)	I did not regularly receive this service before (3)
Speech Therapy (1)	0	0	0
Occupational Therapy (OT) (2)	0	$\circ$	0
Physical Therapy (PT) (3)	0	0	$\circ$
Applied Behavior Analysis Therapy (ABA Therapy) (4)	0	0	0
Social Skills Therapy (5)	0	0	$\circ$
General psychology / Counseling (6)	0	$\circ$	0
Medical visits (e.g. Psychiatry / Developmental Pediatrics / Neurology etc.) (7)	0	0	0
Recreational Therapy (8)	0	$\circ$	0
Vocational Support (9)	0	$\circ$	$\circ$

**122a.** [For each service above, if option (1) is selected]:

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

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

122b. [For each service above, if in question 122a option (a) is selected, then ask]: for the [specify the service depending on prior answer with if logic] that you are 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

**122c**. [For each service above, if in questions 122a option (b) is selected, then ask]: for the [specify the service depending on prior answer with if logic] that you are now receiving via emails or materials sent home, how helpful have you found these accommodations?

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

## 3. Have you needed to access any of the following providers since the Coronavirus (COVID-19) crisis and how did you do so? 123.

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

123a. Please tell us more about what y	ou find helpful / not helpful about telehealth
services, if you have received them:	[TEXT BOX]

- 124. Since the Coronavirus (COVID-19) crisis, what of the following have you experienced overall? Please select all that apply.
  - a. My routine appointments have been canceled or postponed.
  - b. My scheduled procedures or treatments have been canceled or postponed.
  - c. I have had difficulty reaching or speaking to my doctor(s).
  - d. I have had trouble accessing my medications or getting prescriptions filled.
  - e. I have had trouble managing or administering my medications.
  - f. I have trouble affording my medications, treatments, or therapy.
  - g. I have lost access to a clinical trial.
  - h. Other (Please specify)
  - i. None of the above
- 125. Are you prescribed any medications for *mental health or behavior* concerns? (Yes/No)
  - a. If Yes:
    - 125a. Which options would be the most helpful to best manage your 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
- 126. Are you prescribed any other medications for *physical health?* (Yes/No)
  - 126a. Which options would be the most helpful to best manage your 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

### **GENERAL IMPACT**

- 127. Which one of the following statements best describes your current status? (Please check one).
  - a. Everything is fine, I am not in crisis at all.
  - b. Everything is fine, but sometimes I have difficulties.
  - c. Things are sometimes stressful, but I can deal with problems if they arise.
  - Things are often stressful, but I am managing to deal with problems when they arise.

- e. Things are very stressful, but I am getting by with a lot of effort.
- f. I have to work extremely hard every moment of every day to avoid having a crisis.
- g. I won't be able to handle things soon. If one more thing goes wrong I will be in crisis.
- h. I am currently in crisis, but am dealing with it myself.
- I am currently in crisis, and have asked for help from crisis services. (Emergency room, hospital, community crisis supports).
- j. I am 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 you, your friends, or your family.

[TEXT BOX]

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

[TEXT BOX]