The **C**o**R**onav**I**ru**S** Health **I**mpact **S**urvey (CRISIS) - **A**dapted for **A**utismand **R**elatedNeurodevelopmentalconditions (AFAR)- V0.5.1

*Parent/Caregiver/Informant Baseline Form (21+ years)*

**Attribution License:** CC-BY-4.0 (<https://creativecommons.org/licenses/by/4.0/>)

**Development team for core CRISIS Survey:**

The CRISISquestionnaires 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:**

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

*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.

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

*Developers of the adult/youth self-report and the parent-report for autistic adults/adults with autism and related neurodevelopmental conditions*: Meng-Chuan Lai, Ami Tint, Yona Lunsky, Patrick Jachyra, Hsiang-Yuan Lin, Stephanie Ameis

*Editing and Technical Support*: Evdokia Anagnostou, 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 ([merikank@mail.nih.gov](mailto:merikank@mail.nih.gov) and [Adriana.DiMartino@childmind.org](mailto:Adriana.DiMartino@childmind.org), respectively) though this is not required. We also encourage voluntary data sharing for the purpose of psychometric studies that will be led by Dr. Stringaris ([argyris.stringaris@nih.gov](mailto:argyris.stringaris@nih.gov)). Please, contact [Adriana.DiMartino@chidmind.org](mailto:Adriana.DiMartino@chidmind.org) if you would like to make de-identified data contributions for the CRISIS AFAR

*Identification Number:*

**Country:**

**State/Providence/Region:**

**Your age (years):**

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

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

## BACKGROUND:

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

1. **What is your relationship to your family member with a developmental disability**?
   1. Mother
   2. Father
   3. Grandparent
   4. Aunt/Uncle
   5. Foster Parent
   6. Sibling
   7. Other: Specify\_\_\_\_
2. **Please specify the sex of your family member with a developmental disability at birth:** 
   1. Male
   2. Female
   3. Other \_\_\_\_
3. **Please specify the gender of your family member with a developmental disability:**

Man

Woman

Trans man

Trans woman

Non-binary

1. Identity not listed (please specify: \_\_\_\_\_\_)
2. **Thinking about what you know of the family history of your family member with a developmental disability, which of the following best describes the geographic regions from where their ancestors (i.e. great-great-grandparents) came from? You may select as many choices as needed.**
   1. England, Ireland, Scotland or Wales
   2. Australia – not of Aboriginal or Torres Strait Islander descent
   3. Australia – of Aboriginal or Torres Strait Islander descent
   4. New Zealand – not of Maori descent
   5. New Zealand – of Maori descent
   6. Northern Europe including Sweden, Norway, Finland and surrounding countries
   7. Western Europe including France, Germany, the Netherlands and surrounding countries
   8. Eastern Europe, including Russia, Poland, Hungary and surrounding countries
   9. Southern Europe including Italy, Greece, Spain, Portugal and surrounding countries
   10. Middle East including Lebanon, Turkey and surrounding countries
   11. Eastern Asia including China, Japan, South Korea, North Korea, Taiwan and Hong Kong
   12. South-East Asia including Thailand, Malaysia, Indonesia, Singapore and surrounding countries
   13. South Asia including India, Pakistan, Sri Lanka and surrounding countries
   14. Polynesia, Micronesia or Melanesia including Tonga, Fiji, Papua New Guinea and surrounding countries
   15. Africa
   16. North America - not of First Nations, Native American, Inuit or Métis descent
   17. North America - of First Nations, Native American, Inuit or Métis descent
   18. Central or South America
   19. Don’t know
   20. Other
3. **Is your family member with a developmental disability of Hispanic or Latino descent - that is, Mexican, Mexican American, Chicano, Puerto Rican, Cuban, South or Central American or other Spanish culture or origin?**
   1. Yes
   2. No
4. **What is the highest level of education your family member with a developmental disability completed?**
   1. Some grade school
   2. Some high school
   3. High school diploma or GED (General Educational Development test)
   4. Some college or 2-year degree
   5. 4-year college or university graduate
   6. Some school beyond college
   7. Graduate (e.g. master’s, PhD) or professional degree
5. **What is the highest level of education YOU completed?**
   1. Some grade school
   2. Some high school
   3. High school diploma or GED (General Educational Development test)
   4. Some college or 2-year degree
   5. 4-year college or university graduate
   6. Some school beyond college
   7. Graduate (e.g. master’s, PhD) or professional degree
6. **What is the highest level of education the second parent/caregiver of your family member with a developmental disability completed?**
   1. Some grade school
   2. Some high school
   3. High school diploma or GED (General Educational Development test)
   4. Some college or 2-year degree
   5. 4-year college or university graduate
   6. Some school beyond college
   7. Graduate (e.g. master’s, PhD) or professional degree
   8. No second parent/caregiver
7. **Which best describes the area in which your family member with a developmental disability lives?**
   1. Large city
   2. Suburbs of a large city
   3. Small city
   4. Town or village
   5. Rural area

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

Attends college/university part time

Attends college/university full time

Works part time

Works full time

Attends day program

Volunteers

1. No structured day time activity
2. **Where does your family member with a developmental disability live?**
   1. By themselves and fully independent
   2. By themselves and partially independent, requiring some essential support
   3. In a group home
   4. In an institutional setting that is not a group home (e.g., hospital, nursing home)
   5. With me
   6. With other family members
   7. With friends or other roommates
3. **How many people currently live in the home of your family member with a developmental disability (excluding your family member with a developmental disability)**? \_\_\_
4. **Please specify their relationship(s) to your family member with a developmental disability (check all that apply):**
   1. One parent
   2. Two parents
   3. Grandparents
   4. Siblings
   5. Other children
   6. Other relatives
   7. Unrelated person
5. **Are any adults living in the home an ESSENTIAL WORKER (e.g., healthcare, delivery worker, store worker, security, building maintenance)? (Yes/No)**
6. 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)**

1. **How many rooms (total) are in the home of your family member with a developmental disability?** \_\_\_
2. **Is your family member with a developmental disability covered by health insurance?**
   1. Yes, military
   2. Yes, employer-sponsored
   3. Yes, individual
   4. Yes, Medicare
   5. Yes, Medicaid or CHIP
   6. Yes, other
   7. No
3. **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?**
4. Yes
5. No
6. **How tall is your family member with a developmental disability? \_\_\_ centimeters(cm)/inches(in)**
7. **How much does your family member with a developmental disability weigh? \_\_\_ kilograms(kg)/pounds(lbs)**
8. **How would you rate the overall physical health of your family member with a developmental disability?**
   1. Excellent
   2. Very Good
   3. Good
   4. Fair
   5. Poor
9. **How would you rate the overall mental/emotional health of your family member with a developmental disability?**
   1. Excellent
   2. Very Good
   3. Good
   4. Fair
   5. Poor
10. **Has a health or educational professional ever told you that your family member with a developmental disability had any of the following health conditions (check all that apply)?**
    1. Seasonal allergies
    2. Asthma or other lung problems
    3. Heart problems
    4. Kidney problems
    5. Immune disorder
    6. Diabetes or high blood sugar
    7. Cancer
    8. Arthritis
    9. Frequent or very bad headaches
    10. Epilepsy or seizures
    11. Serious stomach or bowel problems
    12. Serious acne or skin problems
    13. Vision problems
    14. Hearing problems
    15. Obsessive compulsive disorder
    16. Emotional or mental health problems such as Depression or Anxiety
    17. Problems with alcohol or drugs
    18. Intellectual disability
    19. Autism spectrum disorder
    20. Learning disorder
    21. Attention-deficit/hyperactivity disorder
    22. Other problems requiring special education services
    23. Other neurodevelopmental conditions
    24. Developmental delay
    25. Known genetic conditions
    26. None of the above

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

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

No words/does not speak

Uses single words meaningfully (for example, to request)

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:**

1. **… has your family member been exposed to someone likely to have Coronavirus/COVID-19? (check all that apply)**
   1. Yes, someone with positive test
   2. Yes, someone with medical diagnosis, but no test
   3. Yes, someone with possible symptoms, but no diagnosis by doctor
   4. No, not to my knowledge
2. **… has your family member been suspected of having Coronavirus/COVID-19 infection?**
   1. Yes, have had positive test
   2. Yes, medical diagnosis, but no test
   3. Yes, has had some possible symptoms, but no diagnosis by doctor
   4. No symptoms or signs
3. **… has your family member had any of the following symptoms? (check all that apply)**
   1. Fever
   2. Cough
   3. Shortness of breath
   4. Sore throat
   5. Fatigue
   6. Loss of taste or smell
   7. Eye infection
   8. Other \_\_\_
   9. None of the above
4. **… has anyone in your family member’s family been diagnosed with Coronavirus/COVID-19? (check all that apply)**
   1. Yes, member of household
   2. Yes, non-household member
   3. No
5. **… have any of the following happened to your family member because of Coronavirus/COVID-19 pandemic? (check all that apply)** 
   1. Fallen ill physically
   2. Hospitalized
   3. Put into self-quarantine with symptoms
   4. Put into self-quarantine without symptoms (e.g., due to possible exposure)
   5. Lost or been laid off from job
   6. Reduced ability to earn money
   7. Passed away
   8. None of the above

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

1. **…. being infected** **by Coronavirus / having COVID-19?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
2. **… his/her friends or family being infected** **by Coronavirus / having COVID-19?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
3. **… his/her *physical health* being inﬂuenced by Coronavirus/COVID-19?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
4. **… his/her *mental/emotional health* being inﬂuenced by Coronavirus/COVID-19?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
5. **How much is your family member asking questions, reading, watching content, or talking about Coronavirus/COVID-19?**
   1. Never
   2. Rarely
   3. Occasionally
   4. Often
   5. Most of the time
   6. Not applicable due to my family member’s limited communication
6. **Has the Coronavirus/COVID-19 crisis in your area led to any positive changes in your family member’s life?**
   1. None
   2. Only a few
   3. Some

* **If answered b or c to question 33, please specify what these positive changes are: \_\_\_\_**

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

**During the PAST TWO WEEKS:**

1. **… how much time has your family member spent going outside of the home (e.g., going to stores, parks, etc.)?**
   1. Not at all
   2. 1-2 days per week
   3. A few days per week
   4. Several days per week
   5. Every day
2. **… how stressful have the restrictions on leaving home been for your family member?**
   1. Not at all / no changes
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
3. **…has cancellation of important events (such as birthday parties, graduation, prom, vacation, etc.) been difficult for your family member?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
4. **… to what degree have changes related to the Coronavirus/COVID-19 crisis in your area created financial problems for your family member or your family?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
5. **… to what degree is your family member concerned about the stability of his/her living situation?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
   6. Unknown due to my family member’s limited communication
6. **… to what degree is your family member worried whether his/her food would run out because of a lack of money?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
   6. Unknown due to my family member’s limited communication
7. **How hopeful is your family member that the Coronavirus/COVID-19 crisis in your area will end soon?**
   1. Not at all
   2. Slightly
   3. Moderately
   4. Very
   5. Extremely
   6. Unknown due to my family member’s limited communication

**Thank you for completing the questions above.**

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

## DAILY BEHAVIORS (THREE MONTHS PRIOR TO CRISIS)

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

1. **... entertain self appropriately for at least 20 minutes?**
2. Independently (without support, prompting, or supervision)
3. With moderate supervision (some verbal and/or visual reminders)
4. With close supervision (support including step-by-step instruction)
5. Not at all
6. **…structure/initiate daily activities (e.g., started and completed schoolwork/homework/chores, followed general schedule of completing activities)?**
7. Independently (without support, prompting, or supervision)
8. With moderate supervision (some verbal and/or visual reminders)
9. With close supervision (support including step-by-step instruction)
10. Not at all
11. **…** **...complete self-care activities (e.g., got dressed/changed independently/brushed teeth/bathe/shower daily) and/or start day’s activities?**
12. Independently (without support, prompting, or supervision)
13. With moderate supervision (some verbal and/or visual reminders)
14. With close supervision (support including step-by-step instruction)
15. Not at all
16. **…manage mealtime and food-related needs (e.g., preparing, organizing, and cleaning up)?**
    1. Independently (without support, prompting, or supervision)
    2. With moderate supervision (some verbal and/or visual reminders)
    3. With close supervision (support including step-by-step instruction)
    4. Not at all

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

1. **… on average, what time did your family member go to bed on WEEKDAYS?**
2. Before 8 pm
3. 8 pm-10 pm
4. 10 pm-12 am
5. After midnight
6. **… on average, what time did your family member go to bed on WEEKENDS?**
7. Before 8 pm
8. 8 pm-10 pm
9. 10 pm-12 am
10. After midnight
11. **… on average, how many hours per night did your family member sleep on WEEKDAYS?**
    1. <6 hours
    2. 6-8 hours
    3. 8-10 hours
    4. >10 hours
12. **… on average, how many hours per night did your family member sleep on WEEKENDS?**
    1. <6 hours
    2. 6-8 hours
    3. 8-10 hours
    4. >10 hours
13. **…on average, did your family member have difficulties falling asleep (e.g., within 20 minutes) after going to bed?**
    1. Not at all
    2. Rarely (less than once a week)
    3. Occasionally (once or twice a week)
    4. Often (three or more times a week but not daily)
    5. Regularly (daily)
14. **…on average, did your family member wake up and remain awake during the night after falling asleep?**
    1. Not at all
    2. Rarely (less than once a week)
    3. Occasionally (once or twice a week)
    4. Often (three or more times a week but not daily)
    5. Regularly (daily)
15. **… how many days per week did your family member exercise (e.g., increased heart rate, increased rate of breathing) for at least 30 minutes?**
    1. None
    2. 1-2 days
    3. 3-4 days
    4. 5-6 days
    5. Daily
16. **… how many days per week did your family member spend time outdoors?**
    1. None
    2. 1-2 days
    3. 3-4 days
    4. 5-6 days
    5. Daily

**BEHAVIORS AND INTERESTS (THREE MONTHS PRIOR TO CRISIS)**

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

1. **…engage in repetitive motor mannerisms/movements (e.g., repetitive movements of the whole body, or just with their hands and fingers)?**
2. Not at all
3. Rarely
4. Occasionally
5. Often
6. Regularly
7. **…engage in sensory seeking behaviors (e.g., visually inspecting things, touching or feeling things for a long time)?**
8. Not at all
9. Rarely
10. Occasionally
11. Often
12. Regularly
13. **…engage in other rituals or routines?**
14. Not at all
15. Rarely
16. Occasionally
17. Often
18. Regularly
19. **…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)?**
    1. Not at all
    2. Rarely
    3. Occasionally
    4. Often
    5. Regularly
20. **…require family members and others he/she interacts with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior (e.g., takes longer to complete tasks, changes schedule to accommodate your family member)?**
21. Not at all
22. Rarely
23. Occasionally
24. Often
25. Regularly
26. **…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)?** 
    1. Not at all
    2. Rarely
    3. Occasionally
    4. Often
    5. Regularly

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

1. **… have any of the following been a significant problem in your family member’s behavior (that was not already controlled by treatment before)? Please check all that apply:**
   1. Hyperactivity
   2. Difficulty staying on task
   3. Getting angry or losing temper easily
   4. Verbal aggression
   5. Physical aggression to others or to property
   6. Deliberately injuring self
   7. Arguing often
   8. Crying easily
   9. Being excessively worried about social situations (e.g., going to a planned activity, speaking publicly)
   10. Being excessively worried on separating from parent/ caregiver
   11. Seeming excessively fearful
   12. None of the above

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

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

* 1. Slightly
  2. Moderately
  3. Very Much
  4. A lot

## MEDIA USE (THREE MONTHS PRIOR TO CRISIS)

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

1. **…watching TV or digital media (e.g., Netflix, YouTube, web surfing)?**
   1. No TV or digital media
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours
2. **...using social media (e.g., Facetime, Facebook, Instagram, Snapchat, Twitter, TikTok)?**
   1. No social media
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours
3. **…playing video games?**
   1. No video games
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours

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

1. **…engage in online/text/email/phone call/video chat interactions with peers outside the household (other than video games)?**
   1. Not at all
   2. Rarely
   3. Occasionally
   4. Often
   5. Regularly
   6. Not Applicable (e.g., no opportunity)
2. **…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)?**
   1. Not at all
   2. Rarely
   3. Occasionally
   4. Often
   5. Regularly
   6. Not Applicable (e.g., no opportunity)

**Thank you for answering the questions above.**

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

## DAILY BEHAVIORS (PAST TWO WEEKS)

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

1. **…entertain self appropriately for at least 20 minutes?**
2. Independently (without support, prompting, or supervision)
3. With moderate supervision (some verbal and/or visual reminders)
4. With close supervision (support including step-by-step instruction)
5. Not at all
6. **…structure/initiate daily activities (e.g., started and completed schoolwork/homework/chores, followed general schedule of completing activities)?**
7. Independently (without support, prompting, or supervision)
8. With moderate supervision (some verbal and/or visual reminders)
9. With close supervision (support including step-by-step instruction)
10. Not at all
11. **…complete self-care activities (e.g., got dressed/changed independently/brushed teeth/bathe/shower daily) and/or start day’s activities?**
12. Independently (without support, prompting, or supervision)
13. With moderate supervision (some verbal and/or visual reminders)
14. With close supervision (support including step-by-step instruction)
15. Not at all
16. **…manage mealtime and food related needs (e.g., preparing, organizing, and cleaning up)?**
    1. Independently (without support, prompting, or supervision)
    2. With moderate supervision (some verbal and/or visual reminders)
    3. With close supervision (support including step-by-step instruction)
    4. Not at all

**DURING THE PAST 2 WEEKS**

1. **...on average, what time did your family member go to bed on WEEKDAYS?**
2. Before 8 pm
3. 8 pm-10 pm
4. 10 pm-12 am
5. After midnight
6. **… on average, what time did your family member go to bed on WEEKENDS?**
7. Before 8 pm
8. 8 pm-10 pm
9. 10 pm-12 am
10. After midnight
11. **… on average, how many hours per night did your family member sleep on WEEKDAYS?**
    1. <6 hours
    2. 6-8 hours
    3. 8-10 hours
    4. >10 hours
12. **… on average, how many hours per night did your family member sleep on WEEKENDS?**
    1. <6 hours
    2. 6-8 hours
    3. 8-10 hours
    4. >10 hours
13. **…on average, did your family member have difficulties falling asleep (e.g. within 20 minutes) after going to bed?**
    1. Not at all
    2. Rarely (less than once a week)
    3. Occasionally (once or twice a week)
    4. Often (three or more times a week but not daily)
    5. Regularly (daily)
14. **…on average, did your family member wake up and remain awake during the night after falling asleep?**
    1. Not at all
    2. Rarely (less than once a week)
    3. Occasionally (once or twice a week)
    4. Often (three or more times a week but not daily)
    5. Regularly (daily)
15. **… how many days per week did your family member exercise (e.g., increased heart rate, increased rate of breathing) for at least 30 minutes?**
    1. None
    2. 1-2 days
    3. 3-4 days
    4. 5-6 days
    5. Daily
16. **… how many days per week did your family member spend time outdoors?**
    1. None
    2. 1-2 days
    3. 3-4 days
    4. 5-6 days
    5. Daily

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

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

1. **…engage in repetitive motor mannerisms/movements (e.g., repetitive movements of the whole body, or just with their hands and fingers)?**
2. Not at all
3. Rarely
4. Occasionally
5. Often
6. Regularly
7. **…engage in sensory seeking behaviors (e.g., visually inspecting things, touching or feeling things for a long time)?**
8. Not at all
9. Rarely
10. Occasionally
11. Often
12. Regularly
13. **…engage in in other rituals or routines?**
14. Not at all
15. Rarely
16. Occasionally
17. Often
18. Regularly
19. **…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)?**
    1. Not at all
    2. Rarely
    3. Occasionally
    4. Often
    5. Regularly
20. **…require family members and others he/she interacts with to maintain specific routines, rituals, habits, including doing things consistently, and requiring warning or change in family behavior (e.g., takes longer to complete tasks, changes schedule to accommodate your family member)?**
21. Not at all
22. Rarely
23. Occasionally
24. Often
25. Regularly
26. **…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)?** 
    1. Not at all
    2. Rarely
    3. Occasionally
    4. Often
    5. Regularly

**DURING THE PAST TWO WEEKS**

1. **…have any of the following been a significant problem in your family member’s behavior (that was not controlled by treatment)? Please check all that apply:**
   1. Hyperactivity
   2. Difficulty staying on task
   3. Getting angry or losing temper easily
   4. Verbal aggression
   5. Physical aggression to others or to property
   6. Deliberately injuring self
   7. Arguing often
   8. Crying easily
   9. Being excessively worried about social situations (e.g., going to a planned activity, speaking publicly)
   10. Being excessively worried on separating from parent/ caregiver
   11. Seeming excessively fearful
   12. None of the above

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

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

* 1. Slightly
  2. Moderately
  3. Very Much
  4. A lot

## MEDIA USE (PAST TWO WEEKS)

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

1. **… watching TV or digital media (e.g., Netflix, YouTube, web surfing)?**
   1. No TV or digital media
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours
2. **... using social media (e.g., Facetime, Facebook, Instagram, Snapchat, Twitter, TikTok)?**
   1. No social media
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours
3. **… playing video games?**
   1. No video games
   2. Under 1 hour
   3. 1-3 hours
   4. 4-6 hours
   5. More than 6 hours

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

1. **…engage in online/text/email/phone call/video chat interactions with peers outside the household (other than video games)?**
   1. Not at all
   2. Rarely
   3. Occasionally
   4. Often
   5. Regularly
   6. Not Applicable (e.g., no opportunity)
2. **…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)?**
   1. Not at all
   2. Rarely
   3. Occasionally
   4. Often
   5. Regularly
   6. Not Applicable (e.g., no opportunity)

## SERVICES

**Thank you for answering the questions above.**

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

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

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

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

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

Using telehealth (Zoom, Skype, phone conversations)

Through emails and materials sent to my family member’s home

By a teacher, behaviorist, or therapist coming to my family member’s home

Through in-person appointments outside of the home

***89b.*** *[For each service above, if in question 89a option (a) is selected, then ask]:*

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

* 1. Not helpful at all
  2. A little helpful
  3. Somewhat helpful
  4. Extremely helpful

***89c****. [For each service above, if in questions 89a option (b) is selected, then ask]:*

***for the*** *[specify the service depending on prior answer with if logic]* ***that your family member is now receiving via emails or materials sent home*, how helpful have you found these accommodations?**

* + - * 1. Not helpful at all
        2. A little helpful
        3. Somewhat helpful
        4. Extremely helpful

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

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

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

1. **Since the coronavirus (COVID-19) crisis, what of the following have you experienced overall? Please select all that apply.**
   1. My family member’s routine appointments have been canceled or postponed.
   2. My family member’s scheduled procedures or treatments have been canceled or postponed.
   3. I have had difficulty reaching or speaking to my family member’s doctor(s).
   4. I have had trouble accessing my family member’s medications or getting prescriptions filled.
   5. I have had trouble managing or administering my family member’s medications.
   6. I have trouble affording my family member’s medications, treatments, or therapy.
   7. My family member has lost access to a clinical trial.
   8. Other (Please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   9. None of the above
2. **Is your family member prescribed any medications for *mental health or behavior* concern? (Yes/No)**
   1. **If Yes:**

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

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

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

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

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

**GENERAL IMPACT**

1. **Which one of the following statements best describes the current status of your family? (Please check one).** 
   1. Everything is fine, my family and I are not in crisis at all.
   2. Everything is fine, but sometimes we have our difficulties.
   3. Things are sometimes stressful, but we can deal with problems if they arise.
   4. Things are often stressful, but we are managing to deal with problems when they arise.
   5. Things are very stressful, but we are getting by with a lot of effort.
   6. We have to work extremely hard every moment of every day to avoid having a crisis.
   7. We won’t be able to handle things soon. If one more thing goes wrong - we will be in crisis.
   8. We are currently in crisis but are dealing with it ourselves.
   9. We are currently in crisis and have asked for help from crisis services. (Emergency room, hospital, community crisis supports).
   10. We are currently in crisis, and it could not get any worse.
2. **Is there someone else in the family for whom you are also the major caregiver?***For example, this could be a baby or small child, an elderly parent, a spouse who is unwell, someone else with a disability, etc.* **(Yes/No)**
3. **If yes:**

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

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

## ADDITIONAL CONCERNS AND COMMENTS

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

**[TEXT BOX]**

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

**[TEXT BOX]**