

## Attachment N. CYSHCN Family/Caregiver Interviews

### Interview Guide – CYSHCN Protocol

Form Approved

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### INTRODUCTION

Thank you for taking the time to meet with me today. My name is \_\_\_\_\_ and I am working with your doctor and others who work in this practice/organization to find out how families who have children with special health needs get the information they need during emergencies and disasters that disrupt their lives or require special things to do to protect their health. We are particularly interested in how you get information during different types of incidents, from whom you'd like to receive that information, and what you most need or want to know. We plan to share our findings and make recommendations to government emergency response agencies, as well as doctors and other providers, so they are better equipped to communicate with families like yours before, during and after emergencies.

The interview should take about one hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments.

All responses will be kept private. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time.

Are there any questions about what I have just explained?

Are you willing to participate in this interview?

\_\_\_\_\_ Interviewee Witness Date

\_\_\_\_\_ Legal guardian (if interviewee is under 18)

**\*Respondents will be asked to fill out a brief survey prior to the interview, which asks about demographics and the special medical needs of their child/children.**

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### Demographic/Background Questions

I'd like to ask you some questions about your family so I understand the challenges you face and the types of communication that will be important to you during an emergency.

1. Tell me about your family.
  - a. How many people live in your household?
  - b. How many children (total and with ASD)?
    - i. What are their ages?
2. Tell me about your child's/children's special health care needs.
  - a. What kinds of special needs or disabilities has he/she been diagnosed with?
  - b. Does he/she rely on any electrical medical devices?
  - c. Does he/she rely on any assistive technology? If so, what type?
    - i. Does this assistive technology rely on electricity? If so, do you have a back-up power source?
      1. If yes, what is it? Roughly how long can that power source last?
      2. If not, what is the main reason you don't have one?
  - d. Does he/she receive any services in the home (e.g. behavioral therapy, speech training, occupational therapy)?
    - i. If yes, how many hours per week?
  - e. Where does your child usually get health care?

Now I'd like to learn more about how you get health-related information.

3. How do you get information about health issues that affect your child?
4. What sources do you trust?
5. What channels (methods) do you use?

### Disasters & Information Seeking:

Now I'd like to ask you about your experience with emergencies and disasters.

6. Have you done any thinking about planning or preparing you family for an emergency or disaster?

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- a. If yes
    - i. How do you learn more about how your family can prepare for an emergency or disaster? What sources, channels do you use? What kind of information do you look for?
    - ii. Have you made a disaster plan? What does this plan consist of? Have you practiced it?
    - iii. How have you communicated this plan to your child (children) with special health care needs?
    - iv. Has anyone discussed disaster preparedness with your child with special health care needs outside of the home (e.g. school, behavioral therapy)?
  - b. If no, why not? What are the barriers for your family (e.g. not an urgent concern, time, cost, need additional information)
7. What information do you need most to help prepare your family for a disaster that could impact your child with special needs?
- a. Who do you think is the best source of information to help you prepare for an emergency or disaster?
8. Do you use social media?
- a. **If yes:**
    - i. What platforms do you use?
    - ii. What kind of information do you get from these channels? Who do you follow?
    - iii. Do you ever use it to get information about emergencies or disasters?
      1. Before, during, or after an event? If so, from which sources do you get information?
  - b. **If not**, what are your reasons for not using it?

### Scenario-specific questions

Now I'd like to ask you some questions about specific types of emergency incidents that could happen and might affect your community or your family. Please know that we are just asking about hypothetical situations and have no information that any of these events will actually occur.

**\*Note: Scenarios will be rotated so that participants are only asked about two scenarios during a given interview.**

### #1 - Storm

**A major storm occurs, causing flooding, downed trees, and long-term (more than one-day) power outages, requiring you to stay home for several days, perhaps without electricity or usual outside help:**

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9. How would this impact you?
  - a. What are your greatest concerns if this type of event were to happen?
  - b. What information would you most want to know?
10. Where would you go for up-to-date information?
  - a. From whom would you want to receive information? How would you get it?
  - b. Would you share information with others (e.g., friends, family, and neighbors)? How?
11. Do you feel prepared to get through an event like this?
  - a. If not, what do you need most to get your family ready?

**An emergency that requires you to leave your home (such as a flood, or fire, or prolonged power outage).**

12. How would this impact you?
  - a. What are your greatest concerns if this type of event were to happen?
  - b. What information would you most want to know?
13. What information would you need to feel comfortable going to a shelter with your family?  
(*Prompt: Would you know what to bring?*)
14. If there was a mandatory evacuation order issued, would you evacuate your family? If no, why not?
  - a. What information would compel you to leave your home? From whom would the guidance or directive need to come?
15. Do you feel prepared to get through an event like this?
  - a. If not, what do you need most to get your family ready?

### #2 - Infectious Disease Outbreak

**There is an outbreak of an infectious disease (like a new type of flu) that is spreading in your community and causing very severe illness.**

16. How would this impact you?
  - a. What are your greatest concerns if this type of event were to happen?
  - b. What information would you most want to know?
17. Where would you go for up-to-date information?
  - a. From whom would you want to receive information? How would you get it?

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- b. Would you share information with others (e.g., friends, family, and neighbors)? How?
18. If there was a medication or shot that was being recommended for this outbreak, what would you want to know before you would get it for your child?
- a. From whom would you want to receive information? How?
19. Do you feel prepared to get through an event like this?
- a. If not, what do you need most to get your family ready?

### # 3 - Nuclear Power Plant Accident

#### **An accident occurs at a nuclear power plant in Pennsylvania and radiation may have been released.**

20. How would this impact you?
- a. What are your greatest concerns if this type of event were to happen?
  - b. What information would you most want to know?
21. Where would you go for up-to-date information?
- a. From whom would you want to receive information? How would you get it?
  - b. Would you share information with others (e.g., friends, family, and neighbors)? How?
22. How would you react if your child was at school and local authorities recommended that everyone remain where they are?
- a. What concerns would you have?
  - b. Would you comply with this recommendation? Why or why not?
    - i. If not, what would make you comply with this recommendation?
23. Do you feel prepared to get through an event like this?
- a. If not, what do you need most to get your family ready?

### Prior Experience with Emergencies

24. Have you ever experienced an emergency like a major storm or event that disrupted your family's life, either requiring you to leave your home, or stay at home for several days without power or your usual supports?
- a. If so, what was it?
    - i. What information did you need (or wish you had) to get through the event?
    - ii. How did you recover from that event?
    - iii. Following the event, what information did you need to return to your usual or normal state of being? Did you get it, from whom? If this were to happen again, how would you want to get information and from whom, both during and afterwards?
  - b. If not, how sure are you that your family could recover effectively (get back to normal) from an event like this?

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- i. Following the event, what information would you need to return to a normal state of being? Who would you want to hear from? How would you get that information?

### Recap

25. When it comes to emergencies and disasters what are your biggest concerns for your family and children?
  - a. What are the biggest challenges for your family with respect to getting through emergencies?
  - b. What would help you to overcome these challenges?
  
26. What information do you need most to help prepare your family for a disaster that could impact your child with special health care needs? What do you most want to know?
  - a. Who do you think is the best source of information to help you prepare for an emergency or disaster?
  - b. How would you like to get that information?
  
27. What would you like us to tell the government agencies and other public safety partners who are in charge of organizing the response to emergencies?
  - a. What do they need to know about you and your needs?
  - b. About how best to get you information before disasters? During and after?

### **Is there anything more you would like to add?**

END OF INTERVIEW:

I'll be analyzing the information you and others gave me and we'll be summarizing our findings and developing recommendations and communication tools for the organizations and health care providers to help them communicate during emergencies with families with special health care needs. We'll also be testing these tools and possible messages at the end of the project with families like yours, to be sure we get feedback from people who need information the most during emergencies and disasters.

Thank you for your time.