

Attachment J. CYSHCN Family/Caregiver Survey

Form Approved

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Dear Parent,

Families with children who have special health needs can have major challenges during disasters. The Centers for Disease Control and Prevention (CDC) wants to make sure that these families can be safe and healthy when a disaster happens.

The CDC is working with the Pennsylvania Chapter of the American Academy of Pediatrics and Drexel University to survey families so that they know what kind of information families need for their children during disasters. The answers to this survey will be used to help the government, your doctors, and community groups get families the information they need to help keep their children safe during disasters.

The survey should take you 15 minutes to complete.

If you have more than one child with special health care needs, please think about all of them when answering the questions in this survey.

Part 1. General Questions – Socio Demographics

1. How many children (17 and younger) do you have?
 0 1 2 3 4 5 More than 5
2. How many children with special health care needs do you have?
 0 1 2 3 4 5 More than 5
3. Please provide the age of your child with special health care needs (in years): _____
(If you have more than one child with special health care needs, please list the age (in years) of each of your children (e.g., 12, 6))
4. My relationship to the child with special health care needs in my care is (if you have multiple children with special health care needs, select all that apply):
 - Mother
 - Father
 - Foster parent or guardian
 - Sister/Brother
 - Grandparent
 - Other (please specify): _____
5. Please indicate which, if any, disabilities or special health care needs your child has (please select all that apply):
 - Speech or communication disability

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- Mobility challenges (physical disabilities)
- Hearing challenges
- Vision challenges
- Respiratory challenges (e.g., needs oxygen, or ventilator, or tracheostomy care, etc.)
- Asthma
- Severe allergies
- Needs nutritional support and equipment (e.g., feeding tube)
- Long-term (minimum six months) daily prescription medicine
- Intellectual disability
- Developmental disability
- Autism spectrum disorder
- Behavioral condition (e.g., ADHD)
- Emotional condition (e.g., Anxiety disorder)
- Diabetes
- Other (please specify): _____

6. Do any of your children with special health care needs take medications (other than vitamins) every day?

- Yes
- No

7. Does your child have any electrical medical devices that are required for his/her health?

If Yes:

Select the devices that your child requires: (Select all that apply)

- Feeding pump
- Drug infusion pump
- Oxygen or oxygen concentrator
- Ventilator
- Other lung support device (BIPAP/CPAP)
- Asthma nebulizer
- Pulse oximeter
- Apnea monitor
- Breathing or heart monitor
- Communication device (ipad, dynavox etc.)
- Other (please specify): _____

If devices are selected:

For any the medical device(s) selected above, do you have a back-up source of power (e.g., back-up battery, generator)?

- Yes
- No
- Don't Know

If Yes: Roughly how long can that back-up power source last?

- _____ hours
- Don't Know

8. Does your family have home health care support (e.g., home health aid, nurse visits) or use a medical daycare for any of your children?

- Yes
- No

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If yes: How many hours per week? _____ hours

9. Where does your child with special health care needs usually get health care? (Check all that apply)
- My child's primary care provider
 - Hospital emergency department
 - Specialist doctor or practice (e.g., lung specialist, neurologist)
 - A hospital outpatient clinic
 - Community health center
 - Urgent care/minute clinic
 - A school nurse
 - Other (please specify): _____
10. What language do you prefer to get information when there is an emergency or disaster?
- English
 - Spanish
 - Other (please specify): _____

Part 2. Emergency Preparedness & Information Seeking

For the next questions, think about an emergency or disaster that could affect the health of your child with special health care needs.

11. Have you made a plan for an emergency or disaster that affects the health of your child with special health care needs?
- Yes
 - No

If Yes: Which of the following do you have a plan for? (**Select all that apply**)

- Staying at home during a disaster that causes a long-term (one or more days) power outage
- Evacuating your home and going to a friend or family member's house
- Evacuating your home and going to a hotel
- Evacuating your home and going to a hospital
- Evacuating your home and going to a shelter
- Communicating with family members during a disaster
- Other: _____

If Yes: Have you practiced, used, or updated this plan in the past 6 months?

- Yes
- No

If No: What are the reasons you do not have a plan?

- Have never thought to do so
- Don't believe it's necessary
- Don't know how
- Don't have the time
- Not enough money to buy what I need to prepare
- Don't Know
- Other (please specify): _____

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12. Who do you think is the **best** source of information to help you **prepare** for an emergency or disaster that affects the health of your child with special health care needs? (**Select up to three sources**):

- Your child's doctor
- Your child's care coordinator
- Your child's social worker
- Your child's home care agency
- Your child's medical equipment provider
- Your child's school
- Place of worship (church, mosque, synagogue)
- Another parent
- American Red Cross
- Health department or emergency management agency
- Federal Emergency Management Agency (FEMA) or Centers for Disease Control and Prevention (CDC)
- Other (please specify): _____

13. What information do you most need to **prepare** for an emergency or disaster that affects the health of your child with special health care needs? (**Select up to three items that are most important to you**)

- How to prepare a disaster kit (e.g., a kit of supplies, medications and other necessary items that you can take if you have to leave your home or use if unable to leave).
- How to get or use a back-up power source
- How to develop a family communication plan
- How to develop an evacuation plan
- How to get a medical summary/care plan of your child's needs
- Where to go if you have to leave your home
- Other (please specify): _____
- Don't need any information
- Don't know what I need

14. Do you subscribe (through text or email) to any of the emergency notification or alert systems (eg. Ready Philadelphia, ReadyPA, Ready Region) that are operated by the state or local emergency management agency in your community?

- Yes (if yes, please indicate which you subscribe to): _____
- No
- Don't Know

15. Have you signed up for a "Special Needs" Registry that is run by government agencies in your community?

- Yes
- No
- Don't Know

16. Have you communicated with your local police, fire department or 911 dispatch service to let them know you have a child with special health care needs?

- Yes
- No
- Don't Know

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17. Do you have access to the Internet?

- Yes, by cellphone and computer/tablet
- Yes, only be cell phone
- Yes, only by computer/tablet
- No

If no, skip to next section (Part 3)

18. Have you ever visited any of the following websites to get either health or emergency-related information (check all that apply):

- Centers for Disease Control and Prevention (CDC)
- Federal Emergency Management Agency (FEMA)
- Pennsylvania Emergency Management Agency (PEMA)
- Pennsylvania Department of Health (PA DOH)
- Website of your local health department
- Website of your local emergency management agency
- American Red Cross
- Website of your doctor's medical practice
- Other website (specify) _____
- Have not used any websites for emergency preparedness or health information.

19. If you have ever visited any of these websites, when did you do so? (Select all that apply)

- Before an emergency or disaster occurred
- During an emergency or disaster as it was taking place
- After an emergency or disaster had taken place
- Don't Know

20. What social media do you use regularly (at least once a week)? Please select all that apply.

- I do not use social media regularly
- Facebook
- Twitter
- Instagram
- Other (please specify): _____

Who do you follow on social media? (check all that apply)

- Friends
- Family members
- Local/state government (health departments, emergency management, police, fire)
- Federal government organizations (CDC, FEMA)
- News outlets (e.g., TV news channels, newspapers)
- Your doctor(s)
- Celebrities
- Other (please specify): _____

In an emergency or disaster, have you used social media to get information?

- Yes
- No, but I plan to use it to get information in the future
- No
- Don't know

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If yes, which channels did you use? (Select all that apply)

- Facebook
- Twitter
- Instagram
- Other (please specify): _____

If yes, who posted information that was most useful to you? (Select all that apply)

- Friends
- Family members
- Local/state government (health departments, emergency management, police, fire)
- Federal government organizations (CDC, FEMA)
- News outlets (e.g., CNN, newspapers)
- Your doctor(s)
- Other (please specify): _____
- Don't remember/don't know

Part 3. Information Needs During Different Types of Emergencies and Disasters

21. **During** an emergency or disaster, how would you get information? (Select all that apply)

- Television
- Radio
- Website (computer)
- Website (mobile phone)
- Facebook
- Twitter
- Instagram
- Printed newspaper
- Email
- Text message
- Telephone (landline or cell)
- Other (please specify): _____

These next questions ask about your thoughts regarding different types of disasters:

A severe storm in your community causes flooding, downed trees that block roads, and a long (more than one day) power outage.

Please tell us how much you agree with each of the following statements:

	5 Strongly Agree	4 Agree	3 Neutral	2 Disagree	1 Strongly Disagree
An event like this is likely to happen in my community within the next 5 years					
An event like this would be dangerous for					

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my child with special health care needs					
My family is prepared to handle an event like this					

22. If the storm causes you to lose power and your family is unable to leave your home, which of the following information is **most important** to you? **Select up to three options.**

- How to manage if you run out of medications
- How to manage if you run out of supplies
- How to manage if home health aides cannot make it to your home
- How to maintain power to equipment your child needs
- Other (please specify): _____

23. If the storm causes you and your family to evacuate your home, which of the following information is **most important** to you? **Select up to three options.**

- Where to go for shelter
- Whether the shelter can accommodate children with special health care needs
- What to bring to a shelter
- What my family cannot bring to a shelter
- How to get to the shelter if you need transportation assistance
- Other (please specify): _____

24. If a severe storm did occur, whom do you trust **most** to provide you with accurate information about protecting the health of your child with special health care needs? (**Select up to three options**)

- Your child's doctor
- Your child's social worker
- Your child's home care agency
- Your child's medical equipment provider
- Your child's school
- Another parent of a child with special health care needs
- Friends, family, or neighbors
- News outlets (e.g., TV news channels, newspapers)
- Place of worship (church, mosque, synagogue)
- American Red Cross
- Health department or emergency management agency
- Centers for Disease Control and Prevention (CDC)
- Federal Emergency Management Agency (FEMA)
- Other (please specify): _____

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There is an outbreak of an infectious disease, such as a dangerous form of the flu that could lead to pneumonia and breathing problems.

25. Please tell us how much you agree with each of the following statements:

	5 Strongly Agree	4 Agree	3 Neutral	2 Disagree	1 Strongly Disagree
An event like this is likely to happen in my community within the next 5 years					
An event like this would be dangerous for my child with special health care needs					
My family is prepared to handle an event like this					

26. If a new medicine for this disease was recommended for your child, what information would you **most want to know to feel comfortable giving it to your child?** **Select up to three options.**

- Whether your child's doctor recommends taking the medication
- How well the medication works to protect from the disease
- Safety of the medication (e.g. potential side effects)
- Whether the type or dose of medicine differs for children or those with special medical needs
- How is medicine given? (injection, nasal spray, by mouth)
- How much the medicine costs
- Whether friends and family are taking it
- Whether health department or CDC recommends taking the medication
- Other (please specify): _____

27. If a disease outbreak like this were to occur, who would you **trust most** to provide you with information about protecting the health of your child with special health care needs? **(Select up to three options)**

- Your child's doctor
- Your child's social worker
- Your child's home care agency

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- Your child’s medical equipment provider
- Your child’s school
- Another parent of a child with special health care needs
- Friends, family, or neighbors
- News outlets (e.g., TV news channels, newspapers)
- Medical experts in infectious diseases (e.g., via news outlets or community forums)
- Place of worship (church, mosque, synagogue)
- American Red Cross
- Health department or emergency management agency
- Centers for Disease Control and Prevention (CDC)
- Federal Emergency Management Agency (FEMA)
- Other (please specify): _____

An accident occurs at a nuclear power plant somewhere in Pennsylvania or a nearby state. Weather forecasts show that winds carrying radioactive particles are headed toward your community.

28. Please tell us how much you agree with each of the following statements:

	5 Strongly Agree	4 Agree	3 Neutral	2 Disagree	1 Strongly Disagree
An event like this is likely to happen in my community within the next 5 years					
An event like this would be dangerous for my child with special health care needs					
My family is prepared to handle an event like this					

29. If an event like this were to happen in Pennsylvania or a nearby state, what information would you most want to know (select up to three items):

- Whether your community is at risk for radiation exposure
- Safety of food/water in your community
- Whether you need to take special medicines to prevent health effects of radiation
- Whether you need to evacuate (leave your home)
- Whether you need to “shelter in place” – stay in your home for several days
- How radiation causes health problems

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- Safe vs. unsafe levels of radiation
- Whether/where to go for monitoring to check for radiation exposure
- Other (please specify): _____

30. If there was an accident at a nuclear power plant, who would you trust to provide you with information about protecting the health of your child with special health care needs? (**Select up to three**)

- Your child's doctor
- Your child's social worker
- Your child's home care agency
- Your child's medical equipment provider
- Your child's school
- Another parent of a child with special health care needs
- Friends, family, or neighbors
- Medical experts in radiation (e.g., via news outlets or community forums)
- News outlets (e.g., TV news channels, newspapers)
- Place of worship (church, mosque, synagogue)
- American Red Cross
- ~~Your local or state~~ Health department or emergency management agency
- Centers for Disease Control and Prevention (CDC)
- Federal Emergency Management Agency (FEMA)
- Other (please specify): _____

For the final question, think about your family's information needs after an emergency or disaster has occurred.

31. After the emergency or disaster event has ended, what information is **most important** to you in order to continue to protect the health of your family? (**Select up to three options**):

- How to get mental health services
 - Access to support groups
 - Information on services from community organizations
 - How to find resources for children with special health care needs
 - Information on how your family can plan for the next disaster
 - Information about the disaster's overall impact (damage, who was affected, why it happened)
 - Resources for relocation support, insurance claims, financial support
 - Public forum with emergency response agencies and government officials to discuss the disaster
 - Other (please specify): _____
-

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Part 4: Demographics

32. How would you describe your ethnicity?

- Non-Hispanic/Latino
- Hispanic/Latino
- Don't Know
- Prefer not to answer

33. How would you describe your race? Please mark all that apply.

- White
- Black or African American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or other Pacific Islander
- Other (please specify): _____
- Don't Know
- Prefer not to answer

34. What is your highest education level? (Please select one choice)

- Some high school
- High school diploma or GED
- Associate's degree
- Bachelor's degree
- Education beyond Bachelor's (Master's, Doctorate, etc.)
- Prefer not to answer

35. What is your household's combined annual income, meaning the total pre-tax income from all sources earned in the past year?

- Less than \$25,000
- \$25,000 to less than \$35,000
- \$35,000 to less than \$50,000
- \$50,000 to less than \$75,000
- \$75,000 or More
- Don't Know
- Prefer not to answer

36. Please provide the zip code where you live: _____

Thank you for completing the survey! If you would like information about preparing for emergencies, please visit the following websites:

- Centers for Disease Control and Prevention: <https://emergency.cdc.gov>
- Pennsylvania Department of Health, Bureau of Public Health Preparedness: <http://www.health.pa.gov/My%20Health/Emergency%20Preparedness/Pages/default.aspx#.WNUo2xjMyL4>

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- Pennsylvania Emergency Management Agency:
<http://www.pema.pa.gov/Pages/Default.aspx#.WNUpOxiMyL4>
- Pennsylvania Chapter, American Academy of Pediatrics: <http://www.paaap.org>