

## Attachment K. ASD Family/Caregiver Survey

### Autism – Parent Network Survey

Form Approved

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Dear Parent,

Families with children who have an autism spectrum disorder 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 A.J. Drexel Autism Institute 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 an autism spectrum disorder, please think about all of them when answering the questions in this survey.*

#### **Part 1. General Questions – Demographics**

1. How many children (age 17 and younger) do you have?  
 0     1     2     3     4     5     More than 5
  
2. How many children do you have who have been diagnosed with an autism spectrum disorder?   
0     1     2     3     4     5     More than 5
  
3. Please provide the age of your child with an autism spectrum disorder (in years): \_\_\_\_\_ (If you have more than one child with autism spectrum disorders, please list the age (in years) of each of your children an Autism Spectrum Disorder (e.g., 12, 6)
  
4. My relationship to the child with autism spectrum disorder in my care is (if you have multiple children with an autism spectrum disorder, select all that apply):
  - Mother
  - Father
  - Foster parent or guardian
  - Sister/Brother
  - Grandparent
  - Other (please specify): \_\_\_\_\_

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5. Has your child ever been diagnosed with any of the following? Check all that apply:
- Autism Spectrum Disorder (Autism, Asperger's, PDD-NOS)
  - Epilepsy and/or seizures
  - Intellectual Disability (formerly called Mental Retardation)
  - Fragile X Syndrome
  - Attention Deficit Hyperactivity Disorder (ADHD)
  - Anxiety (obsessive compulsive disorder, phobias, panic disorder, generalized anxiety disorder)
  - Depression
  - Learning Disability
  - Cerebral Palsy
  - Tourette's/Tic Disorder
  - Other (please specify) \_\_\_\_\_
6. How clearly does your child speak? Would you say he/she:
- Has no trouble speaking clearly
  - Has a little trouble speaking clearly
  - Has a lot of trouble speaking clearly
  - Does not speak at all
  - Don't know
7. How well does your child communicate by any means (e.g., verbal communication, sign language, adaptive technology, etc.)? Would you say he/she:
- Has no trouble communicating
  - Has a little trouble communicating
  - Has a lot of trouble communicating
  - Does not communicate at all
  - Don't know
8. How well does your child understand what people say to him/her? Would you say he/she:
- Has no trouble understanding others
  - Has a little trouble understanding others
  - Has a lot of trouble understanding others
  - Does not understand others at all
  - Don't know
9. What types of service needs does your child with an autism spectrum disorder have? Check all that apply:
- Occupational Therapy
  - Physical Therapy
  - Speech and Language Therapy
  - Behavioral Therapy
  - Assistive technology for speech
  - Other (please specify) \_\_\_\_\_

*If you checked any of the above, how many hours of therapy (total) does your child have per week? \_\_\_\_\_ hours*

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10. Do any of your children with autism spectrum disorders take medications (other than vitamins) every day?

- Yes
- No

11. What type of school does your child with Autism Spectrum Disorders attend?

- Attends school for children/youth with intellectual/developmental challenges
- Attends public/private school for general population, participates in at least one special education class
- Attends public/private school, mainstreamed in all classes
- Other (specify): \_\_\_\_\_

12. Do any of your children have any electronic medical devices or communication devices that are required for his/her health?

If Yes:

What type of device does your child require: \_\_\_\_\_

13. For any of the devices listed 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

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

- Yes
- No

If yes: How many hours per week? \_\_\_\_\_ hours

15. Where does your child with autism spectrum disorders usually get health care? (Check all that apply)

- My child's primary care provider (community practice)
- Hospital emergency room
- Specialist doctor or practice (Developmental Pediatrician, Psychologist, Neurologist, Psychiatrist)
- A hospital outpatient clinic
- Urgent care
- A school nurse

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- Other (please specify): \_\_\_\_\_

16. In what language do you prefer to get information when there is an emergency or disaster?

- English
- Spanish
- Other (please specify): \_\_\_\_\_

### **Part 2. Emergency Preparedness and Information Seeking**

For the next questions, think about an emergency or disaster that could affect the health of your child on the autism spectrum.

17. Have you made a plan for an emergency or disaster that affects the health of your child with an autism spectrum disorder?

- Yes
- No

*If Yes:* Which of the following have you created 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): \_\_\_\_\_

18. Who do you think is the **best** source of information or advice to help you **prepare** for a disaster or emergency that affects the health of your child with an autism spectrum disorder? (**Select up to three sources**)

- Your child's doctor
- Your child's care coordinator
- Your child's social worker

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- Your child's home care agency
- Your child's medical equipment provider
- Your child's therapist
- 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)
- Advocacy organization for families with autism spectrum disorders (e.g., such as Autism Speaks)
- Other (please specify): \_\_\_\_\_

19. What information do you need to **prepare** for a disaster or emergency that affects the health of your child with an autism spectrum disorder? (**Select up to three items that you think are most important to you**)

- How to prepare a disaster kit (e.g., a kit of supplies, medicines and other necessary items that you can take if you need to leave your home or you can use if you are unable to leave your home)
- How to get 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
- Doctor or medical provider to support and go over the plan
- Other (please specify): \_\_\_\_\_
- Don't know what I need

20. Do you subscribe (through text messaging or email) to any of the emergency notification or alert systems (e.g. Ready Philadelphia, 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

21. Have you communicated with your local police, fire department or 911 dispatch service to let them know you have a child with an autism spectrum disorder or special health care need?

- Yes
- No
- Don't Know

22. Do you have access to the Internet

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

*If no, skip to next section (Part 3)*

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23. 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
- Website of an autism advocacy organization (e.g. such as Autism Speaks)
- Other website (specify) \_\_\_\_\_
- Have not used any websites for emergency preparedness or health information.

24. 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
- Not sure

25. What social media do you use regularly (at least once a week)? (check 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., CNN, 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 about future emergencies
- No
- Don't know/Not sure

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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)
- Don't remember/don't know

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

26. **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): \_\_\_\_\_

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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 my child with autism spectrum disorder					
My family is prepared to handle an event like this					

27. 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): \_\_\_\_\_

28. 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 Autism Spectrum Disorders
- 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): \_\_\_\_\_



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29. If a severe storm did occur that required you to stay at home for several days or leave your home, who would you trust to provide you with accurate information in that situation about protecting the health of your child with an autism spectrum disorder? (Select all that apply)

- 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 an autism spectrum disorder
- Friends, family, or neighbor
- News outlets (e.g., TV news channel, newspaper)
- Place of worship (church, mosque, synagogue)
- American Red Cross
- Local or state health department or emergency management agency
- Centers for Disease Control and Prevention (CDC)
- Federal Emergency Management Agency (FEMA)
- Autism advocacy organization such as Autism Speaks
- Other (please specify): \_\_\_\_\_

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

30. 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					

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31. If a new medicine to prevent 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 like autism
- How is the 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): \_\_\_\_\_

32. 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
- Your child's medical equipment provider
- Your child's school
- Another parent of a child with an autism spectrum disorder
- 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)
- Autism advocacy organization such as Autism Speaks
- Other (please specify): \_\_\_\_\_

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**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.**

33. 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					

34. 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
- Safe vs. unsafe levels of radiation
- Whether/where to go for monitoring to check for radiation exposure
- Other (please specify): \_\_\_\_\_

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35. 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
- My 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
- 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.**

36. 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 local social service agencies
- How to find resources for children with autism spectrum disorders
- 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): \_\_\_\_\_

### **Part 4: Demographics**

37. How would you describe your ethnicity?

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

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

- White
- Black or African American
- American Indian or Alaskan Native
- Asian

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- Native Hawaiian or other Pacific Islander
- Other (please specify): \_\_\_\_\_
- Don't Know
- Prefer not to answer

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

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

40. 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

41. Please provide the zip code where you live: \_\_\_\_\_

Thank you for completing the survey!

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>
- Pennsylvania Emergency Management Agency: <http://www.pema.pa.gov/Pages/Default.aspx#.WNUpOxjMyL4>
- A.J. Drexel Autism Institute: <http://drexel.edu/autisminstitute/>