

The AJ Drexel Autism Institute – All Provider Survey

Form Approved

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Dear Colleague,

Families with children who have an autism spectrum disorder have unique risks during major disasters. Providing these families with clear and targeted communication from trusted sources can be critical to their survival. The Centers for Disease Control and Prevention (CDC) is sponsoring this study to understand the disaster communication needs of families with children with an autism spectrum disorder, and the capacity of medical and other professionals to meet those needs.

CDC is working with the A.J. Drexel Autism Institute and Drexel University to survey providers who work with children and adults with autism spectrum disorders. The information you provide will be used by emergency response agencies, health care and other professionals to improve their ability to communicate with families during emergencies that threaten their health and safety.

Please complete this survey which should take no more than 15 minutes of your time. We thank you for your input.

Part 1. General Agency Questions

1. What type of services do you provide?: (CHECK ALL THAT APPLY)
 Primary Medical Care Social Skills Occupational Therapy Personal Therapy
 Speech/Behavioral Therapy Diagnostics Psychotherapy Medication Management
 Other (please specify): _____

2. How would you characterize your practice or service organization?
 Independently owned and managed, non-profit
 Independently owned and managed, for-profit
 Owned and managed by a health care system
 Government agency or organization
 Academic medical practice in a university or academic health system
 Community health center
 Other (please specify): _____

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3. What is the age range of clients in your organization? Check all that apply:
 < 5 years 5-10 years 10-18 years > 18 years
4. How many clients are currently in your agency?
 < 500 500-1,000 1,000 – 5,000 > 5,000 – 10,000 >10,000
5. How many providers (e.g., include physician assistants, nurse practitioners, therapists) work in your agency? ____ (please estimate number of full-time providers)
6. Does your agency have more than one site? Y or N
- a. If yes, how many? _____
7. In what county (or counties, if multiple sites) is your agency located? _____
8. Does your agency use electronic records or record keeping? Y or N
9. Approximately, what percentage of your agency's practice consists of children/adults with an autism spectrum disorder?
 <10% 10-24% 25-50% >50%
10. What percentage of your clients with Autism are verbal (please estimate):
 <10% 10-25% < 25% 25-50% >50%
11. Do you serve clients that have any of the following disabilities? 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) _____
12. What types of service needs do your clients with Autism Spectrum Disorders have? Check all that apply:
 Occupational Therapy
 Physical Therapy

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- Speech Therapy
- Behavioral Therapy
- Assistive technology for speech
- Other (please specify): _____

13. In what types of settings do your clients/patients with autism spectrum disorders participate in school? Check all that apply:

- Attends school for children/youth with intellectual/developmental challenges
- Attends public/private school for general population, participates in special education classes
- Attends public/private school, mainstreamed in all classes
- Other (please specify): _____

Part 2 Agency Communication Procedures

14. How do individual clients/patients contact the agency if they have treatment related questions? (Check all that apply)

- Telephone
- Portal messaging
- Email
- Fax
- Text message
- Facebook message
- Twitter
- Come into agency (face-to face)
- Other (please specify): _____
- Clients do not contact the agency for questions outside of visits or encounters.

15. Does your agency have a fast way to communicate with ALL of your clients or patients in an emergency?

Y or N

If No, skip to 18

16. If yes, what mechanisms or channels do you use (check all that apply):

- Post information on your website
- Patient Portal
- Email
- Automated phone calls
- Text messaging (group)
- Twitter
- Facebook

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- Add message to organization's voice mail
- Other (specify) - _____

17. If you have the ability to communicate with large numbers of your clients/patients during emergencies, what types of information would you convey? (Select all that apply)

- Changes in hours or location (e.g., open or closed, limited hours, alternative location, etc.)
- Answering service number for patients to reach providers
- Alternative number if answering service is not available
- Information about how to access prescription refills, medical equipment orders
- Availability of a vaccine or medication
- Recommendations for protective measures appropriate for the emergency (e.g., stay at home; go to a shelter, avoid exposure to a type of food if during a foodborne disease outbreak)
- Availability of resources (e.g., more information, supplies) for patients either through practice or in community
- Other (please specify): _____

18. From whom does your agency or practice receive current information (e.g., "situational awareness") about emergencies that will impact your agency's operations or the health of your patients? Check all that apply:

- Pennsylvania Emergency Management Agency (PEMA)
- Local (county or township) emergency management agency
- Pennsylvania Department of Health
- Local health department
- Center for Disease Control and Prevention
- American Academy of Pediatrics (AAP) or other professional society
- Television news local
- Television news national
- Newspaper
- Internet/websites (Please specify: _____)
- Health system central office
- Colleagues (informal networks)
- Facebook
- Twitter
- Radio
- Other (please specify) _____

If Facebook or Twitter selected:

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19. If your practice gets information during emergencies from Facebook or Twitter, what sources are most helpful to you?
- Media outlets
 - Government agencies
 - Health systems
 - Other (please specify): _____
20. Does your practice receive alerts from CDC's Health Alert Network (HAN)? Y or N
21. Do you or your practice receive alerts from your state/local public health department Health Alert Network (HAN)? Y or N
22. Does your practice receive alerts or other information from your state/local emergency management agency alert system? (e.g., Ready PA, or local/county equivalent such as Ready Philadelphia, Ready Erie, or Ready Chesco)
- Yes
 - No
 - Don't Know
23. Does your practice have a back-up generator?
- Yes
 - No
 - Don't Know

Part 3. Emergencies and Children/Youth with Autism Spectrum Disorders

While we recognize that your agency may serve clients/patients with a range of special health care needs, the next few questions ask about how you might assist patients with autism spectrum disorders.

24. Does your agency encourage families with children with autism spectrum disorders to have plans for emergencies? Y or N
25. How would you get information about how the emergency is affecting the health of your patients with autism spectrum disorders? Check all that apply:
- Contact individual families directly by telephone
 - Go to family's home
 - Home health agency/visiting nurses
 - Social service providers
 - Durable Medical Equipment (DME) providers
 - Community or faith-based organizations
 - Other _____

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26. Does your practice have a fast way to communicate during an emergency specifically with multiple patients who have an autism spectrum disorder? Y or N

27. If yes, what mechanisms or channels do you use (check all that apply):

- Patient Portal
- Email
- Automated phone calls
- Text messaging (group)
- Post information on your organization’s website
- Twitter
- Facebook
- Other (specify) - _____

28. Which of the following would be most useful to provide information during disasters to the families in your agency/practice with an autism spectrum disorder?

	5 Very useful	4 Useful	3 Neutral	2 Not very useful	1 No need
List or registry of patients on spectrum who are at risk for poor outcomes during disasters					
Technology that gives the organization/practice the capacity to reach patients urgently (assuming electricity not disrupted)					
Education and training in the health impacts of specific threats and how to mitigate or treat them					
Real-time situational awareness and information from government agencies to share with patients					
Other (please specify):					

29. In the event of a **major storm or weather event** that disrupts power for several days and interferes with transportation routes, would your agency try to communicate with the families in your practice to provide them with information to help them get through the storm and minimize the impact to their health? (Check all that apply)

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- Yes, would contact all families/clients in the agency
- Yes, would contact the families with an autism spectrum disorder specifically (with information tailored to their needs)
- No, would not do this

30. **In this type of scenario (major storm), which of the following applies to your agency and its plans for communicating with your patients:** (Check all that apply)

- I need more information to advise families in a weather emergency
- I don't believe that it is the agency's responsibility to provide information to patients about how to survive a weather emergency
- I don't believe that patients expect me (the agency) to provide information to them during a weather emergency
- I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
- The agency lacks the technological capacity to do this
- Other (please specify): _____
- None of these apply

31. In the event of a **major infectious disease outbreak** like an influenza pandemic, would your agency try to communicate with the families in your practice to provide them with information to help them minimize the impact to their health?

- Yes, would contact all families in the agency
- Yes, would contact the families with an autism spectrum disorder specifically (with information tailored to their needs)
- No, would not do this

32. **In this type of scenario (major infectious disease outbreak), which of the following applies to your agency and plans for communicating with your patients:** (Check all that apply)

- I need more information to advise families in an infectious disease outbreak
- I don't believe that it is the agency's responsibility to provide information to patients about how to survive an infectious disease outbreak
- I don't believe that patients expect me (the agency) to provide information to them during an infectious disease outbreak
- I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
- The agency lacks the technological capacity to do this
- Other (please specify): _____
- None of these apply

33. If there was an **accident at one of the nuclear power plants** in Pennsylvania (or in a nearby state), would your agency try to contact patients with autism spectrum disorders to convey the

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risks (or lack thereof) to their health and other guidance for health-protective behaviors (e.g., shelter in place, evacuate, take potassium iodide (KI) pills)?

- Yes - would contact all families in the agency
- Yes - would contact the families with an autism spectrum disorder specifically (with information tailored to their needs)
- No, would not do this

34. In this type of scenario (accident at a nuclear power plant), which of the following applies to your agency and plans for communicating with your patients: (Check all that apply)

- I need more information to advise families in this type of disaster
- I don't believe that it is the agency's responsibility to provide information to patients about how to survive this type of disaster
- I don't believe that patients expect me (the agency) to provide information to them during this type of disaster
- I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
- The agency lacks the technological capacity to do this
- Other (please specify): _____
- None of these apply

Part 4. Agency Communication Needs

35. Do you believe that your agency needs additional technology or technological support to expand its capacity for large-scale client communication during emergencies? Y or N

If yes, which of the following would be useful to you?

- Text messaging capacity for multiple recipients
- Automated phone message capacity
- Blast email capacity
- Use of patient portal to send messages for multiple recipients
- Capacity to target communications to subsets of clients
- Other (specify) _____

36. Do you believe that **you or your agency/practice** would benefit from trainings or guidance regarding how to communicate with clients who have autism spectrum disorders before or during emergencies? Y or N

****If no, skip to end of survey***

37. If yes would training or guidance related to any of the following be useful:

	5 Very useful	4 Useful	3 Neutral	2 Not very useful	1 No need for this
Accessing up-to-date information from official sources (e.g., emergency management/public health) during emergencies					
Availability of services for clients during emergencies					
Preparing clients for emergencies					
Using social media					
Using technologies for rapid communications with clients					
Understanding disaster Information needs of families					
Addressing psychological needs during disasters					

Other educational needs (please specify): _____

38. If yes, what formats for guidance or trainings would be useful to you? (Check all that apply)

- e. Webinars
- f. Websites with communication tools, checklists
- g. Conferences (in person) with didactic trainings
- h. Publications (available electronically) with recommendations for communicating with those with autism spectrum disorders during emergencies
- i. Agency guidelines and toolkits to facilitate large-scale communications during emergencies with clients
- j. Maintenance of certification modules (including Part IV Learning collaborative)

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- k. On-site technical assistance to improve agency capacity for client communications during emergencies
- l. Other formats? Please specify: _____

Thank you for completing this survey. The results will be shared with government emergency response agencies and with health and social service agencies, and used to develop communication protocols that support clients with autism spectrum disorders before, during and after disasters.

The following resources are available for agencies that would like additional information regarding emergency planning, communications during emergencies and disasters, and how to prepare clients with autism spectrum disorders:

1. AAP Children and Disasters website
<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/default.aspx>
2. Pediatric Practice communications toolkit
<http://diversitypreparedness.org/browse-resources/resources/CPHRC%20Pediatric%20Toolkit/>
3. Practice Emergency Planning Materials
<http://bit.ly/2pgEFHO>
4. Checklists for patients with SHCNs
<http://bit.ly/2pgEFHO>
5. Helping a Child Living with Autism to Deal with Disaster-
<https://www.autismspeaks.org/family-services/autism-safety-project/helping-children-respond-disaster>

Information in emergencies:

6. PA HAN registration
<https://han.pa.gov/>
7. CDC HAN registration
<https://emergency.cdc.gov/han/updates.asp>
8. Ready region/Ready PA
<http://www.pema.pa.gov/planningandpreparedness/readypa/pages/readypa.aspx>