Focus Group Interview Guide – Health Care/Social Service Providers – Autism Spectrum Disorders

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Introduction

Thank you for taking the time to meet with me today. My name is _____. I work at Drexel University in the Center for Public Health Readiness and Communication. I am working with the Centers for Disease Control and Prevention (CDC), the AJ Drexel Autism Institute, and the Pennsylvania Chapter of the American Academy of Pediatrics to understand the disaster communication needs of families of children with autism spectrum disorders, and the capacity of organizations and practices to meet those needs. We want to learn how you communicate with the patients or clients you serve, and what you perceive to be their greatest needs, especially regarding information during disasters. We want to identify any best practices you currently use as well as communication challenges that we can address with this study.

The goal of this project is to develop guidelines and tools for families, emergency response agencies, health care and social service providers to facilitate communication during emergencies with families of children autism spectrum disorders. We plan to test these tools and guidelines at the end of the project with each of these groups to be sure they meet your needs as providers and improve your capacity for crisis communication to these families.

This focus group brings together health care and social service agency representatives who work with people with autism spectrum disorders. In addition to this focus group, we'll be having similar discussions with government and non-profit emergency response and public safety agencies, as well as experts in health information technology. We are also conducting at least 20 interviews with families and individuals with autism spectrum disorders.

This session should take no more than 90 minutes. I will be taping the discussion 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 leave the conversation at any time.

Are there any questions about what I have just explained?

Are you willing to participate in this focus group?

General Questions – Demographics of Participants

To get started, I'd like to get a sense of where each of you works and your job or role in the organization. No information that identifies either you or your agency will be included in our summary or final report.

Please introduce yourself and include your professional role (e.g., physician, social worker, DME provider, nurse, case manager, behaviorist, speech or physical therapist, etc.). If you can, please share the percentage of clients/patients in your practice with autism spectrum disorders.

I.   **General Communication Practices**
       (*Note: In focus group, have everyone answer first question – short answer*)

1. How do you get information to your clients/patients regarding health issues in general? During in-person/encounters/appointments? And when clients/patients not in office?

2. How do you receive information from patients outside of their appointments (or encounters) – how do they contact you? (e.g. electronic system; phone, etc,)

3. Does your agency or organization use social media to communicate with patients/clients? If so, how? (*Ask specifically about FB, Twitter, other channels, bi-directionality, who they follow, etc.*)
    a. Do patients use social media to communicate with you? If so, what types of info, which channels?

4. How would you describe the added challenges with communication that children/adults with autism spectrum disorders experience? How do you communicate with your patients who have autism spectrum disorders? Please speak to your approach during patient/client encounters and to other types of communications outside of encounters. (*Ask if they use panel or registry to identify persons with autism spectrum disorders and if so, ask how patients are selected*.)

II.   **Communication with ASD Patients during Emergencies**
5. During emergencies or disasters, in addition to the types of communication you mentioned earlier, what other means do you use to communicate with families or individuals with autism spectrum disorders when they need information or must take special actions to protect their health?

Let's consider some specific types of emergencies:

6. Think about a major weather event with a power outage, and disruption of transportation routes: (**In focus group, generate a list on flipchart)**
    a. What do you think are the biggest challenges that someone with an autism spectrum disorder would face in that event?
    (*Ask specifically about how a long-term shelter in place impacts them. How does an evacuation order impact them?*)
    b. How would you communicate with your high-risk patients to help them prepare? Or to get through/recover from the event?
    c. How do you think your patients want to get information in this type of situation? (**Ask participants to name a few ways.**) From whom?
7. Think about a community-wide outbreak of an infectious disease that can cause severe illness, like a new strain of influenza.
    a. What do you think some of the greatest challenges that persons with autism spectrum disorders will face in that event?
    b. How would you communicate with your high-risk patients if there was a vaccine or medication they needed, or a specific health behavior that was advised for them?
    c. How do you think your patients want to get information in this type of situation? (**Ask participants to name a few ways.**) From whom?

8. Think about an accident at a nuclear power plant nearby, with potential radiation release:
    a. What do you think some of the greatest challenges that persons with autism spectrum disorders will face in that event?
    b. How do you communicate with your high-risk patients if there a specific health behavior that was advised for them?
    c. How do you think your patients want to get information in this type of situation? (**Ask participants to name a few ways.**) From whom?

III. **Risk and Capacity Perceptions**
9. How prepared are your patients for these types of incidents?

10. What do you think are the greatest challenges or needs during emergencies for the high-risk patients and families you serve? (**In focus group, generate a list on flipchart.**)

11. What do you think are the types of emergencies that most concern your patients? (In other words, **what are your patients worried about**?)

12. Any success stories or examples when there were emergencies and your practice (e.g., your office, and your clients or patients) handled them well?

13. How else can your practice help your patients prepare for or get through emergencies?

14. What do you or does your practice need to help you communicate with your high-risk patients during emergencies that threaten their health? (*Prompts can include: technology, better information, communication with emergency response agencies/public safety experts, training in types of emergencies or use of communication tools*)

15. What would you like us to convey to 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 your patients?
    b. About you and how you can help?

16. **Is there anything more you would like to add?**

<u>END OF FOCUS GROUP</u>

Thank you very much for your time. We will analyze the information you and others gave me and summarize our findings. We will then develop recommendations and communication tools for the organizations and health care providers to use with their patients with ASD during emergencies. We'll also test these tools and messages at the end of the project with disaster response agencies, providers, and families , to get feedback from people who need information the most during emergencies and disasters.