

SUPPORTING STATEMENT

Part B

Effective Communication in Public Health Emergencies - Developing Patient Centered Tools for Children and Youth with Special Health Care Needs and Individuals with Autism Spectrum Disorders

Date: 02/07/18

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B. Collection of Information Employing Statistical Methods

Section 1: Respondent Universe and Sampling Methods

This protocol will utilize a multi-method approach to data collection to study the communication needs of two target populations during disasters: families with children and youth with special health care needs (CYSCHN); and families, caregivers with children who have Autism Spectrum Disorders, and individuals with Autism Spectrum Disorders (ASD). We will also assess the disaster communication practices and capacity of health care and other professionals who serve these families and individuals. Data collection will consist of surveys, focus groups, and interviews. We will include the following cohorts of individuals in Pennsylvania in the research to accomplish the study objectives: The Center for Public Health Readiness and Communication at Drexel University is located in Philadelphia, Pennsylvania. The investigators for this project have strong working relationships with the clinical and public safety agency communities in Pennsylvania and surrounding region, which will facilitate the convenience sample recruitment strategy for interviews and focus groups. In addition to reaching providers in Pennsylvania, the project may also include professionals from New Jersey and Delaware. Public safety agencies and health care professionals in the state and Philadelphia metropolitan region have extensive experience responding to natural disasters and to mass gathering/special events that can impact the lives of individuals with special health care needs. The selection of this region for this study allows investigators to benefit from that experience.

The Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) coordinates a model statewide program for pediatric medical practices that serve children with special health care needs (the Pennsylvania Medical Home Initiative); the chapter has also conducted programs to address the emergency preparedness needs of this population. In addition, the St. Christopher's Hospital Medical Center's Center for Children with Special Healthcare Needs is one of the largest clinical programs in the country serving this high-risk population, with over 2,500 patients. This partnership between Drexel University, the PA AAP, and St. Christopher's Hospital takes advantage of the unique expertise and experience of these organizations and allows us to work with an especially vulnerable population that is often difficult to reach. The state of Pennsylvania is one of the largest in the country, with over 12 million residents in both rural and urban areas and who represent many different social and economic backgrounds. The study findings are thus likely to be broadly generalizable to the general population of the United States.

- 1) Families (i.e., parents and caregivers) of CYSCHN and ASD, youth (e.g., adolescents between 13-18 years) with special health care needs, including ASD
- 2) Adults with ASD
- 3) Medical, social service, and other health care and professional providers who serve CYSCHN and individuals with ASD

To capture the perspectives and communication capacity of individuals and agencies charged with leading response efforts and minimizing untoward health outcomes by sharing important

health and safety information with these high-risk groups during emergencies, we will also collect data from:

- 1) Representatives from emergency response and public safety agencies in Pennsylvania, such as local and state public health, emergency management and emergency medical services organizations, American Red Cross and other voluntary organizations active in disasters
- 2) Experts in health information and health communications technology in Pennsylvania

This study is exploratory in nature and not intended to be representative of all families of children with special health care needs. As there is little published information about the disaster communication needs of these populations, we seek to begin to understand the unique information needs of these high-risk, vulnerable populations during disasters.

The final study sample for all the surveys, focus groups, and interviews will be those who can complete at least one or more questions with analyzable results.

The total number of subjects accrued in both protocols is expected to be **930**:

Type of Data Collection	Number of Participants
CYSHCN Family/Caregiver Survey	150 respondents
CYSHCN Provider Survey	250 respondents
CYSHCN Family/Caregiver (and youth with SHCN) Interviews	50 respondents
CYSHCN Provider Focus Groups (2)	20 respondents
CYSHCN Family/Caregiver Focus Groups – Evaluation (2)	20 respondents
CYSHCN Provider Focus Group -Evaluation (1)	10 respondents
CYSHCN Sub-total	500 respondents
ASD Family/Caregiver Survey	200 respondents
ASD Provider Survey	150 respondents
ASD Family/Caregiver/Individual Interviews (includes youth/adults with ASDs)	30 respondents
ASD Provider Focus Group (1)	10 respondents
ASD Family/Caregiver Focus Group – Evaluation (1)	10 respondents
ASD Provider Focus Group – Evaluation (1)	10 respondents
ASD Sub-total	410 respondents
Emergency Response Organizations Focus Group	10 respondents
Health IT Focus Group	10 respondents
Total Sample Population	930 respondents

1. A. Quantitative Sample

CYSHCN

- 1) Survey of parents of children with special health care needs (**Total 150 responses**):

- a. Email distribution of link to electronic web-based survey to parents in Parent Partner Network of the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) Medical Home Initiative (MHI), a statewide practice network in Pennsylvania. This MHI is a project supported by the PA AAP; participating practices provide augmented care and services to children with special health care needs through a multidisciplinary team (N=150, anticipate 30% response rate; n = 50 responses)
 - b. Email distribution of survey to partner networks of the Pennsylvania Chapter of the American Academy of Pediatrics (estimate an additional 1,000 recipients, with a 10% response rate for n = 100 responses):
 - i. PEAL Center (Family to Family Health Information Center)
 - ii. Epilepsy Foundation
 - iii. Special Kids Network
 - iv. Parent to Parent organization
 - v. Family Voices
 - vi. Visions for Equality
- 2) Survey of providers (**Total 250 responses**):
- a. Email distribution (electronic survey) to pediatrician members of PA AAP (N=2,000, anticipate 10% response rate or 200 responses)
 - a. Paper survey – Email/in-person distribution to pediatric practices that participate in the PA AAP Medical Home Initiative (N=165, anticipate 30% response rate or 50 responses)
Note: overlaps with PA AAP statewide membership listserv recipients. Recipients will be instructed to complete survey once only.

ASD

- 2) Survey of parents: (**Total 200 responses**)
- a. Email distribution of web-based survey sent to parents in the A.J. Autism Institute listserv (N= 1,000 family/patient recipients; anticipate response rate of 10% = 100 responses). *Note: overlaps with Drexel listserv recipients. Recipients will be instructed to complete survey once only.*
 - b. Email distribution (electronic survey) of web-based survey to Autism Society of America, a partner organization of A.J. Drexel Autism Institute – Parent listserv (N= 2,000, anticipate 5% response rate or 100)
- 3) Survey of providers (**Total 150 responses**)
- a. Email distribution of web-based survey to A.J. Drexel Autism Institute listserv – estimate total N=600 provider recipients (anticipate 20% response rate or 120 responses, including providers, patients, families, and other stakeholders)
 - b. Email distribution of web-based survey to providers in A.J. Drexel Autism Institute community providers working group (N= 15) and the social work network (N= 75) (total = 90; anticipated response 30% or 30 responses)

1. B. Qualitative Sample

Recruiting of subjects for interviews and focus groups will rely on referrals from the practice networks operated by the co-Investigators (Turchi and Plumb) and the networks operated by their organizational partners. Recruiting will occur through practices and providers, using snowball sampling recruiting methods and convenience samples, but guided by the frameworks described below with respect to participant characteristics. Because the goal of this project is to understand the disaster communication needs of the highest risk families who are likely to have the most severe impact following disasters, we will work with our Co-Investigators and collaborators to enroll subjects with a range of medical conditions with different complexity and needs and who reflect geographic diversity (i.e., urban vs rural, access to children's hospital). We will also work to include subjects who have limited English proficiency (LEP); and who reflect socioeconomic diversity and thus differential access to resources to assist them with emergency preparedness and capacity to respond. Across the sample, we will also work to include subjects who have survived a major disaster (e.g., Superstorm Sandy) and who can share their experiences and communication challenges during that event. A framework for anticipated enrollment for the CYSCHN interviews and focus groups is presented below:

CYSCHN: Framework for subject selection – Interviews/focus group with Families and Caregivers (and Adolescents) (n = 50 subjects):

- 1) Children with access, mobility challenges (physical disabilities), reliance on assistive technology (n = 15)
 - a. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity), range of ages (includes adolescents)
- 2) Children with intellectual, developmental delay, communication challenges, including vision and hearing impaired, behavioral challenges (n = 10)
 - a. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity), range of ages (includes adolescents)
- 3) Children with chronic illnesses (e.g., asthma, epilepsy, sickle cell, diabetes) (n = 25)
 - a. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity), range of ages (includes adolescents)

Similarly, the subject selection for interviews and focus groups with families and individuals with Autism Spectrum Disorders will include individuals across the age spectrum, including adolescents and adults (who we plan to interview directly, obtaining consent from family members and assent from individuals themselves, as necessary), as well as individuals/families with a range of social and economic needs, including individuals from culturally diverse groups, historically underserved populations, those with limited English proficiency, and those with economic challenges. We plan to recruit individuals through medical practices and social service providers who collaborate with the A.J. Drexel Autism Institute. We will ask our partners to limit selection and recruitment to individuals (when individuals are to be interviewed directly) who are not intellectually impaired and who can provide informed consent.

A framework for anticipated enrollment in interviews is presented below:

Autism Spectrum Disorders: Framework for patient selection – Interviews with Individuals/Parents and Caregivers (n = 30 subjects):

- 1) Children on spectrum (n = 20)
 - a. High Functioning (Based on school placement, service utilization, communication abilities)
 - i. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity)
 - b. Severe impact (Based on school placement, service utilization, communication abilities)
 - i. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity)
- 2) Adults on spectrum (n = 10)
 - a. High Functioning (Based on school placement, service utilization, communication abilities, living situation)
 - i. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity)
 - b. Severe impact (Based on work/school participation, service utilization, communication abilities, living situation)
 - i. To include individuals from each category: English/LEP, geographic diversity (urban/rural), socioeconomic diversity (income, education, racial and ethnic diversity)

Professional Providers, Emergency Response Organizations, Health Information Technology Experts: Framework for Recruiting: Focus Groups and Interviews

We will recruit providers through the practices and organizations that are affiliated with (or who collaborate or partner with) the PA AAP, the A.J. Autism Institute, and the Clinic for CYSCHN at St. Christopher's Hospital for Children. We will use snowball sampling recruitment strategies with a convenience sample.

We will recruit participants from emergency response organizations from the Philadelphia metropolitan area and surrounding Mid-Atlantic states, by reaching out to prior collaborators and partners in previous projects. This will be a convenience sample using snowball sampling recruitment methods, to include individuals who work for local and state public health, emergency management and Emergency Medical Service organizations, as well as public safety agencies like the American Red Cross. Similarly, recruiting for health information technology experts will rely on snowball sampling methods and include a convenience sample of individuals already known to the research team and project partners in health care and academic settings in Pennsylvania and the Philadelphia metropolitan region.

Focus Groups/Interviews with Families and Providers for Message Testing and Evaluation

During the last phase of this project (year 3), we will convene a series of focus groups and if necessary, one-on-one interviews with parents/caregivers, affected individuals, and providers in

the CYSCHN and ASD community to provide feedback on the project deliverables, including proposed communication protocols, guidelines, and messages. Participants will be invited by project investigators, based on same criteria used for data collection, to ensure a cross-representation of individuals (and families) living with ASDs as well as provider type. Provider focus groups will also include a sample of emergency response agency representatives. These participants may be individuals who participated during the data collection or first phase of the study, or new subjects.

Section 2: Procedures for the Collection of Information

2.A Quantitative Data Collection

CYSHCN

Survey of Families: We will survey parents and family members of CYSHCN by distributing a web-based electronic survey via email to the “Parent Partner Network” of the PA AAP Medical Home Initiative, a parent advisory group of approximately 150 parents that supports and advises the PA AAP Medical Home Initiative (MHI), which is a statewide practice network in Pennsylvania that provides augmented care and services to children with special health care needs through a multidisciplinary team.

In addition, the PA AAP will forward this web-based survey to other parent networks in AAP partner organizations that serve children and youth with special health care needs, including children with epilepsy, physical and intellectual disabilities. The recruitment email for the survey as well as the survey itself is attached (Attachments C and J). The survey will be available in Spanish to allow recipients in the Parent Partner Network to complete the survey if their primary language is Spanish. There will be a link to a Spanish version of the instrument, and the initial email will include an invitation in Spanish to participate.

Survey of Medical Providers: Using a web-based, electronic survey instrument, we will survey pediatricians and other health care providers (N=2,000) who belong to the PA Chapter of the American Academy of Pediatrics. The survey will be sent via email to the entire Pennsylvania AAP pediatric health care provider membership because all practicing pediatricians provide care for CYSCHN as part of their overall patient population. The CYSHCN provider recruitment email and the provider survey tool itself are provided below (Attachments D and L). The survey will also be made available on additional occasions to pediatrician providers (in person, at MHI project meetings) who participate in the PA AAP Medical Home Initiative.

ASD

Survey of Families and Individuals with ASD: We will survey parents and caregivers of individuals with ASDs, and individuals on the autism spectrum using a web-based survey that will focus on their risk communication needs and preferences during disasters. A link to the survey will be sent via email to the A.J. Drexel Autism Institute’s general listserv that includes patients and families, health care, behavioral health, other service providers, and advocates who have volunteered to receive communications from this Institute. Each respondent will be asked to self-select an affiliation or category (e.g., patient/family or provider) to access one of the two appropriate web-based survey instruments.

The link to the survey developed for parents/families of individuals with ASD will also be sent via email to the parents on the listserv of the national Autism Society of America, a partner of the Drexel Autism

Institute. This listserv distribution reaches several thousand parents and family members of individuals living with ASD across the United States. The recruitment email for the survey as well as the family survey itself is provided below. (Attachments E and K).

Survey of ASD Providers: As noted above, we will survey health care and other service providers by sending a link to a web-based survey to provider-recipients on the listserv of the A.J. Drexel Autism Institute. We will also send this electronic survey to two additional professional advisory networks and working groups that are conducted by the Institute including the Institute's "provider community working group" and "social work network" (approximately 15 and 75 members, respectively). The recruitment email for the survey as well as the provider survey itself is provided below (Attachments E and M).

The surveys will be conducted using Qualtrics, a web-based application. Access to the Qualtrics instrument and data files will be protected by passwords and restricted to the Drexel research team. Data from the Qualtrics program will be downloaded and stored in Microsoft Excel files that will be secured on the Drexel University secure server, protected by both password and restricted user access (e.g., only accessible to the Drexel research team). No protected health information will be collected as part of the surveys. The data will be analyzed using SPSS analytic software. This analysis will focus on descriptive epidemiology and statistics. Analytic methods may be used to explore significant differences in communication preferences between types of groups (e.g., different medical diagnoses or needs; differences in social determinants of health) but this is not the primary purpose of this study.

2.B. Qualitative Data Collection

CYSCHN

Interviews with Families: Investigators will interview a minimum of 50 selected families who have children and youth with special health care needs; adolescents who agree to participate and whose parents/guardians provide consent will also be interviewed. When convenient for families, we may also conduct group interviews with no more than 3-5 parent/caregivers at the same time. All subjects will be asked to complete a brief pre-interview survey that collects demographic information and information about their child(s) special health care need. The interview guide and the pre-interview survey are provided below (Attachments N and V).

The families who will be recruited to participate in interviews and focus groups for the qualitative research in the CSHCN protocol will be recruited from the 2,500 children who receive care in the St. Christopher's Hospital Center for CYSHCN, as well as the children who receive care in the 165 pediatric practices who participate in the PA AAP MHI. They will be recruited by the study Co-Investigator, Dr. Turchi and through the providers at the participating MHI practices throughout Pennsylvania. Recruiting of subjects for interviews and focus groups will rely on the practice networks and the networks operated by their organizational partners. Written information will be provided to the Center for CYSHCN for distribution and explanation, and distributed to selected families (Attachment W). Participants will be selected based on criteria including medical diagnosis (e.g., type of disability and medical need), geographic location of residence (e.g., urban vs rural and proximity to children's hospital), socioeconomic factors, and language spoken at home. These individuals will be selected by the Co-Investigator, working with the clinical providers in the MHI, and will be based on medical record review. Subjects will be recruited during medical visits and also via email (Attachment X).

Focus Groups with Health Care and Other Service Providers: A minimum of two focus groups are planned with pediatric medical providers and other health and social service providers (e.g., including but not limited to social workers, durable medical equipment providers, psychologists, nurses, home health organization staff) who provide health care and support to CYSHCN. To be sure that we capture a wide number of perspectives from providers, we may conduct up to five interviews with medical providers in large (high-volume) pediatric practices who care for CYSHCN throughout the state who may not be able to participate in the scheduled focus group discussions. The focus group guide for these sessions is attached to this proposal (Attachment P).

The PA AAP leadership and Co-Investigator Turchi will guide the recruiting of health care and behavioral health professionals as well as social service, medical equipment, and other service providers who work with CYSHCN. The Co-Investigator and consultant will choose these individuals. This convenience sample will be selected to ensure that they represent a cross-section of the types of health care, social service, and other providers that work with the study populations. The PA AAP and Dr. Turchi (Co-Investigator) will invite providers who are engaged in the CYSCHN program at St. Christopher's Hospital as well as the MHI network to participate in focus groups regarding communication capacity. This group will include a broad network of medical, behavioral, social service, equipment providers, as well as occupational and physical therapists and others who work with CSHCN.

We will convene one focus group with representatives from local and state emergency management, public health, and other public safety agencies, as well as non-governmental agencies such as the American Red Cross, to assess their perceptions of disaster communication needs of the target populations, current methods, and capacity for communication. This will be a convenience sample selected by the project investigators, of individuals working for these agencies in either planning or communications capacities, in Pennsylvania and the surrounding Mid-Atlantic states. The focus group guide and recruitment email are provided below (Attachments S and Y). We will also convene a focus group with health information technology experts. The PA Chapter of the AAP includes members who are subject matter experts in health information technology. PA AAP leadership will identify a convenience sample of members and other stakeholders to participate in a focus group to discuss the roles and capabilities of new and emerging technologies for patient communication during emergencies and disasters. The focus group guide and recruitment email are provided below (Attachments T and Y).

Focus Groups for Message Testing and Protocol Feedback: During the final year of the project, we will convene two focus groups with family members of CYSHCN and with consenting adolescents with SHCN. The purpose of these focus groups will be to test and obtain feedback on the messages and communication tools that we develop to meet their needs during emergencies. These families will be recruited with the same strategy used for data collection, to ensure that they reflect the medical needs, geographic, linguistic, and socioeconomic diversity of all CYSHCN. The guide for these message testing focus groups and the recruitment email are attached to this proposal (Attachments P and Z). One additional focus group is planned to obtain provider feedback on proposed message templates, guidelines, recommendations, and project deliverables. The selection criteria will be another convenience sample of individuals who represent the breadth of health care and other providers who serve these populations, and will also include representation from public safety agencies. The message testing focus group guide and recruitment email are attached to this proposal (Attachments U and Z).

ASD

Interviews with Individuals and Families of Individuals with ASDs: A minimum of 30 individuals and/or families (parents and caregivers) of individuals with ASDs will be interviewed to determine their disaster communication preferences, concerns, and needs during various emergency scenarios. Depending on the participant's preference, these interviews will take place either at the Autism Institute, or virtually, using online platforms including Skype and Google Hangout. Individuals and families will be selected to ensure that the study population provides a cross-representation of all individuals living with ASD in the community, focusing on including individuals in different categories that reflect a range of functional abilities and challenges (e.g., verbal vs. non-verbal, participates in school/mainstream classes or work, reliance on assistive technology). Within each category, we will work to include individuals across the age spectrum, including adolescents and adults (who we plan to interview directly, obtaining consent from family members and assent from individuals themselves, as necessary), as well as individuals with a range of social and economic needs, including individuals from culturally diverse groups, historically underserved populations, those with limited English proficiency, and those with economic challenges. We will also work to include individuals who have directly experienced a major community-wide emergency, such as Superstorm Sandy. The interview guide and the pre-interview survey are each attached to this proposal (Attachments O and V).

Dr. Plumb will work with the provider working groups at the Autism Institute and provider partners to identify patients and families who meet the study criteria (e.g., based on functional status, in addition to criteria such as age, representation of underserved communities, social and economic challenges, limited English proficiency) to invite them to participate in either single or group interviews. In addition, individuals who participate in other studies and activities of the Autism Institute, including the Life Course Outcomes program, will also be invited to participate in interviews. The recruitment email for these interviews is attached to this protocol (Attachment E).

Focus Group with Providers: Co-Investigator Plumb will identify and recruit a cross-section of health care, behavioral health, and social service providers from the A.J. Drexel Autism Institute partner network, who serve individuals and families with ASDs to participate in a focus group. Participants will be part of a convenience sample that will be selected to optimize the representation of the range of providers who work with individuals with ASD in the community. These individuals will be drawn from the Outreach Core listserv network and the Institute's partners. To be sure that we capture a wide number of perspectives from providers, we may conduct up to five interviews with medical providers who may not be able to participate in the scheduled focus group discussions. The recruitment email and the focus group guide itself are attached to this proposal (Attachments E and R).

Focus Group for Message Testing and Protocol Feedback: During the final year of the project, we will convene at least one additional focus group with individuals and family members of individuals with ASD. The purpose of these focus groups will be to test and obtain feedback on the messages and communication tools that we develop to meet their needs during emergencies. These families will be recruited with the same recruitment strategy used for data collection, to ensure that they reflect the medical needs, geographic, linguistic, and socioeconomic diversity of all individuals with ASD. The guide for these message testing focus groups and the recruitment email are attached to this proposal (Attachments P and Z). One additional focus group is planned to obtain provider feedback on proposed message templates,

guidelines, recommendations, and project deliverables. These providers will be recruited with the same recruitment strategy used for data collection, to ensure that their clients reflect the medical needs, geographic, linguistic, and socioeconomic diversity of all individuals with ASD. The message testing focus group guide and recruitment email are attached to this proposal (Attachments U and Z).

Qualitative data collection will include in-person, semi-structured interviews and focus groups which will be audio recorded, transcribed, and stored in Microsoft Word. The data will then be analyzed using NVivo software. After separately examining a portion of the transcripts, two researchers will reach consensus about which themes to examine in detail and will then develop a codebook. Each researcher will independently code a sample of the transcripts to ensure inter-coder reliability. Once an inter-coder reliability of at least .8 is established, the two researchers will code the remainder of the transcripts independently. In qualitative research, saturation of information is emphasized over size or representativeness of the sample.^{1,2} We chose the sample sizes to ensure accuracy of the information we will receive within each of the respondent categories.

Section 3: Methods to Maximize Response Rates and Deal with No Response

3.A Quantitative Data Collection

As a result of our partnerships with the Centers for CYSCHN, the Pennsylvania American Academy of Pediatrics Medical Home Initiative, and the A.J. Autism Institute, we do not anticipate any problems with the identification of participants for the surveys proposed in this study. This study benefits from the resources available to the PA AAP with over 2,200 members, the MHI for CSHCN in Pennsylvania with over 150 participating pediatric practices statewide, and the Center for CYSCHN at St. Christopher's Hospital for Children, with over 2,500 children in care. In addition to patients, these professional partners reach a broad range of medical and health care providers, to whom they will forward the surveys to increase the number of respondents. Similarly, the A.J. Autism Institute has a large stakeholder network of providers, patients/families, and advocates from whom we will draw on for survey completion as well as participation in both focus groups and interviews. We will send at least two follow-up emails to all potential respondents and, if needed, our partners will leverage a range of similar partner networks to broaden the reach of our surveys.

Our mixed method study design also gives a degree of protection if our survey response rates are lower than expected. Our semi-structured interviews, which will take place after the surveys have been completed, are designed to delve deeper into the questions posed in the surveys. We anticipate a low response rate across each of our surveys, as shown below, leading to a potential non-response bias. However, this study is exploratory in nature and not intended to be representative of all families of children with special health care needs. Instead, we seek to begin to understand the unique information needs of these high-risk populations during disasters.

Type of Data Collection	Number of Expected Participants	Size of Network & Expected Response Rate (%)
CYSHCN Family/Caregiver Survey	150 respondents	MHI Parent Partner Network – 150, 30% (50); PA AAP partners – 1,000, 10% (100)

CYSHCN Provider Survey	250 respondents	PA AAP - 2,000, 10% (200); MHI Practices - 165, 30% (50)
ASD Family/Caregiver Survey	200 respondents	A.J. Drexel listserv - 1,000, 10% (100); Autism Society of America - 2,000, 5% (100)
ASD Provider Survey	150 respondents	A.J. Drexel Autism Institute Network - 600, 20% (120); A.J. Drexel Provider and Social Worker Network - 90, 30% (30)

3.B. Qualitative Data Collection

As with our quantitative data collection, we will rely on the extensive networks of our partners to recruit interview and focus group participants. To minimize the burden on individuals interested in participating in our interviews and focus groups, we plan to conduct the interviews at locations that are convenient for patients and families, including the clinic or practice location where they were recruited. Additionally, we can conduct interviews over the phone or through video chat as needed. We are also offering a \$25 gift certificate incentive to all parents, family members, or individuals with a special health care need who participate in an interview or focus group. Our investigator team recently completed research using in-depth interviews of similar populations, and their experience suggests that this incentive strongly encouraged families to participate.

Section 4: Tests of Procedures or Methods to be Undertaken

Each of the surveys and interview/focus group guides were reviewed by all the Co-Investigators, CDC investigators and subject matter experts, and Dr. Vincent Covello, an expert in the field of risk communication. Each of the data collection instruments designed for families of children with special health care needs was reviewed by two members of the Children's Preparedness Unit of the Children's Health Team at CDC. Additionally, the ASD data collection instruments were reviewed by a member of the A.J. Drexel Autism Institute. The CYSHCN interview guide was also reviewed by one parent of a child with special health care needs.

We piloted the CYSCHN family/caregiver survey with three parents of children with special health care needs, and we piloted the CYSHCN provider survey with five providers. In each case, the average response time for completion of the survey was 15 minutes. Minor revisions were made to the data collection instruments based on the feedback from the pilot testing and, where relevant, this feedback was also applied to the ASD data collection instruments.

Section 5: Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following individuals will be involved in the collection of quantitative and qualitative data:

- Esther Chernak, MD, MPH, FACP – Principal Investigator
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- Renee Turchi, MD, MPH, FAAP – Co-Investigator
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- Jennifer Plumb, DSW/LSW – Co-Investigator
 - o 215-571-3838; jcp94@drexel.edu
- Tom Hipper, MSPH, MA
 - o 257-359-6174; tjh87@drexel.edu

In addition to those listed above, the following individual will assist with the data analysis:

- Philip Massey, PhD, MPH
 - o 267-359-6067; pmm85@drexel.edu

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