

Supporting Statement Part A for
Effective Communication in Public Health Emergencies – Developing Community-Centered Tools for
People with Special Health Care Needs v2

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Attachment J – CYSHCN Family/Caregiver Survey

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- The proposed study will: identify the disaster communication needs of families with children and youth with special health care needs (CYSHCN) and families and individuals with autism spectrum disorders (ASD), identifying preferred channels, sources and necessary content; survey and interview families with CYSHCN and ASD regarding preferred communication channels, sources and content; interview providers, emergency response agencies and health information technology experts regarding current communication practices and capabilities; develop communication tools for emergency response agencies and providers to use for families with CYSHCN and ASD during disasters; and assess those tools with stakeholders from affected communities.
- The data resulting from this study will be used to develop specific tools, protocols, and message templates that can be used for communicating during emergencies and disasters with families with CYSHCN and ASD. This study is research and intended to be generalizable to the general study population.
- This collection has two components: (1) surveys of families with CYSHCN, families with ASD, health care and other professional providers for CYSHCN and individuals with ASD, and (2) interviews and focus groups with parents and caregivers of CYSHCN and ASD, with healthcare and other professionals who serve these communities, with emergency response agency representatives, and with experts in health information technology.
- The subpopulations to be studied are families/caregivers with CYSHCN and ASDs, health care and social service professionals, emergency response agency representatives and health technology experts in Pennsylvania and mid-Atlantic states.

A. Justification

1. Circumstances Making the Collection of Information Necessary

Children and youth with special health care needs (CYSHCN), such as access and mobility challenges, chronic illness, intellectual and developmental disabilities, and other communication difficulties, require targeted messages before, during, and after disasters to ensure that they fully appreciate the risks to their health and safety and can take measures to avoid harm. Significant research has highlighted the unique information needs for at-risk populations in general, as well as more specific populations such as minority communities, limited-English proficiency communities, and persons with physical or communication disabilities. However, there has been minimal translation of this research into practical tools for sharing information, nor has the research been extended to the families of CYSHCN, including autism spectrum disorders specifically. Research has also shown that families and individuals are more likely to prepare for emergencies or follow health-related emergency directives when the information comes from a health care professional, particularly someone engaged in their care. There is very little information about the capacity of these trusted sources to reach at-risk individuals during disasters, or their coordination into government risk communication efforts. Finally, although social media is used by at-risk populations every day, relatively little is known about how these populations use social media during disasters, as most of the published literature analyzing channels used by at-risk populations were completed before the widespread use of social media in disasters.

This project will utilize a systems approach to understanding the communication needs of these high-risk communities during disasters, and the perspectives and communication capacity of individuals and agencies charged with leading disaster response efforts. Three research questions inform this project:

- How do families with children and youth with special health care needs and autism spectrum disorders prefer to receive information in emergencies and disasters? What are their preferred channels, formats, and information sources?
- Do medical practices and social service organizations that serve these communities have the capacity for disaster communications? How do current electronic medical records and other technologies support urgent risk communication to at-risk patients or clients?
- To what extent can social media be a useful channel to share information with at-risk communities during a public health emergency?

This study will utilize a multi-tiered, mixed methods approach to data collection to identify the communication needs of two target populations during disasters, including 2 surveys of families with CYSHCN and ASDs; 2 surveys of health care and other professional providers who serve these populations; 50 interviews with families and caregivers of CYSHCN and ASDs; 5 focus groups with professional providers, and emergency response agency representatives, and 5 focus groups for message testing review of proposed communication frameworks and protocols for use during disasters. Throughout the data collection process, the research team will work to include participants with limited English proficiency, limited socioeconomic resources, and limited technology resources.

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.

The data collection is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241), included in this request as Attachment A – Authorizing Legislation. This information collection request is a new request and approval is requested for 24 months, from September 1, 2017 – September 1, 2019.

2. Purpose and Use of the Information Collection

The information collected in this study will inform journal manuscripts and web-based toolkits for emergency communications to be used by state and local public health, emergency management, healthcare, and other service delivery systems who serve families with CYSCHN and ASDs.

The information collected in this study will be used to address three of the research areas of interest related in information management and risk communication in CDC's Broad Agency Announcement: (1) How do audiences use social media to stay informed and share information during public health emergencies? How does this use affect the likelihood of engaging in appropriate health protective behaviors; (2) How can agencies increase compliance with public health recommendations and control measures during epidemics, following disasters, or during other adverse events; and (3) What are the most effective message formats for information sharing for various populations such as at-risk populations, vulnerable populations, including limited English proficiency populations, and individuals without smart phones.

The resulting knowledge and tools will be used by government emergency response agencies to convey critical information to families with CYSCHN and ASDs, and leverage the key roles of trusted health care and other professional providers who serve these communities and who are often their trusted sources of information during public health emergencies. The partnerships between public health and the health care and social service sector is a key component of community preparedness, and highlighted within the Public Health Emergency Preparedness and Healthcare Preparedness capabilities.

This project will investigate how the medical practices and social service agencies that serve these populations communicate with patients during emergencies to prevent morbidity, and identify channels for communication using new technologies like electronic medical record (EMR) platforms, patient portals, social media, and other networks. The research findings will be translated into messages targeted for these audiences in preferred platforms and from preferred sources that will be evaluated by community stakeholders. Deliverables will include guidelines for risk communication directed towards at-risk populations with specific needs during public health emergencies, for use by government agencies and health and social service providers; guidelines for the use of social media as well as other technologies available to organizations or agencies identified as preferred sources for information for at-risk populations; and a communication toolkit that includes specific messages and templates for preferred formats and channels of CYSCHN, addressing all phases of emergency response, including long-term recovery and the 'return' to daily living. The project will also include an evaluation component, during which representatives from families with CYSCHN and ASDs, as well as providers and emergency response agencies will review the proposed guidelines and tools, to inform their revision. This research can strengthen the partnership between the public health and health care/social service sector to improve the outcomes for families with CYSCHN. For CDC, the findings could also inform

guidance and partnerships with health care and professional providers who serve other at-risk communities, to leverage their expertise and their access and trusted status to improve health outcomes during public health emergencies.

This project is funded under a Broad Agency Agreement CDC contract number 200-2016-92427 (09/26/16-09/25/19).

3. Use of Improved Information Technology and Burden Reduction

This information request is in compliance with the Government Paperwork Elimination Act (GPEA), Public Law 105-277, title XVII. A variety of modes will be used as part of a data collection strategy, all of them employing some form of information technology (IT). The surveys will be web-based and conducted electronically, disseminated to subjects via email, permitting electronic submission of responses. Interviews and focus groups will be conducted either in-person or virtually, via telephone or through technology such as Skype or Google Hangout. For these interviews, information will be collected according to an interview guide and recorded. These audio recordings will be forwarded electronically to transcription service and returned to the study team for coding and analysis. Members of the study team will use state-of-the-art computer systems to organize and analyze the information collected.

4. Efforts to Identify Duplication and Use of Similar Information

There are no similar data available for use in this study based on literature search, conference attendance, and communications with other CDC staff. Prior studies have assessed the communication needs of adults with disabilities, as well as the needs of children during disasters, but there are no investigations into the specific needs of families with CYSCHN, nor ASDs specifically. While there are guidelines and recommendations for individuals with functional needs and for children related to emergency preparedness, these recommendations do not touch on CYSCHN, nor on communications for these populations, or the capacity for health care and other professionals to provide information during emergencies. This study will be the first to focus on the communication needs of these specific communities, and to take a systems-based approach to assessing communication capacity and practices of key stakeholders and providers who provide critical, potentially life-sustaining information to these families during disasters that threaten their health. No consultation was done outside CDC.

5. Impact on Small Businesses or Other Small Entities

It is possible that some of the medical practices included in the data collection will be small businesses, though small businesses are not the focus of the project. Questions have been kept to the absolute minimum needed to ensure data integrity and minimize burden on small medical practices. Data collection will be scheduled for times and at locations that are convenient for medical practices, including telephone-based interviews. Further, not including these practices would ignore a significant source of care and support for families with CYSCHN or ASDs.

6. Consequences of Collecting the Information Less Frequently

This request is for a one time information collection. Not collecting this information will limit our understanding of the communication needs of families with CYSCHN or ASDs, and how to address them to prevent injury and illness during public health emergencies. There are no legal obstacles to reducing the burden.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This request fully complies with the regulation 5 CFR 1320.5.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

The Federal Register notice was published for this collection on September 20, 2017, Vol. 82 No. 181, pp. 43984 (Attachment Ba). CDC received two public comments (Attachment Bb). The commenters agreed this project addressed a communication gap that needed to be filled and were supportive. Comments suggested a need to reach out to families of CYSCHN or ASD using a variety of online channels, including social media, and partners already associated with this audience. Concerns included protection of data and suggested increase in burden hours. CDC and PIs responded with further information outlining how they are utilizing a number of online methods and partner organizations to reach and recruit this population for data collection, methods employed to ensure security of data collected, and an explanation that burden hours do not include investigator time to conduct research.

9. Explanation of Any Payment or Gift to Respondents

Families (parents and caregivers; adolescents) who participate in the interviews and focus groups will be offered a \$25 gift card incentive. Families may participate in focus groups together, but we expect that families will generally be represented by one caregiver. One gift card will be provided for each family. Adolescents may participate without direct participation of a parent/caregiver upon completion of an assent form. Participation of adolescents in any interviews and focus groups was included in the family/caregiver category in the burden hours table. Each interview is expected to last approximately 60 minutes. 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. Respondents to the surveys will not be offered payment or gifts for their participation, nor will professional providers and emergency response agency representatives who participate in interviews and focus groups. This study's investigators and other colleagues at Drexel University have completed research using in-depth interviews of individuals and families with children and youth with special health care needs, adolescents, and related populations, and used incentives successfully to facilitate recruitment and participation. See Ness-Cochinwalla M et al. A comparison of providers' and families' viewpoints on discharge tracheostomy education, in *Critical Care Medicine* 2018 (in <https://insights.ovid.com/critical-care-medicine/ccme/2018/01/001/405/371/00003246>); Massey, Philip, Contextualizing an expanded definition of health literacy among adolescents in a health care setting, in *Health Education Research* 2012 (in <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3498601/>); and Turchi, Renee and Massey Philip, Understanding and addressing the impact of low health literacy on the interaction of adolescents with

the health information environment (presentation at Society of Adolescent Health Medicine, 2016 at <https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbnxkcncBoaWxpcG1hc3NleXxneDo2ZGJmMDAyMmYwMjc4N2U0>); and Arana, Evelyn. Racial and ethnic disparities in mammography utilization among women with intellectual and developmental disabilities in *Cancer Epidemiology, Biomarkers and Prevention* 2016 (in http://cebp.aacrjournals.org/content/25/3_Supplement/C28).

Health care, social service, and public safety professionals must communicate with patients and clients before, during and after disasters as part of their professional responsibilities. Participation in this study will help them to fulfill their professional commitments, thus no incentives will be offered to the providers and professionals who participate in the study's focus groups and interviews.

10. Protection of the Privacy and Confidentiality of Information Provided by Respondents

Respondents are informed during the active consent procedures that their responses will be secure and only used by the study team for research purposes (Attachments C, D, E, F, & G). No names or other identifying information will be collected in any of the data collection during this project.

10.1 Privacy Impact Assessment

OPHPR Science Office has reviewed this submission and determined that the Privacy Act does not apply (Attachment H). The surveys will be completed electronically by participants who will not be asked for any information in Identifiable Form (IIF). To enable the interview process, the following information in Identifiable Form (IIF) will be used: Names, addresses, email addresses, and telephone numbers. However, we will not be linking interview responses to this personal information. No CDC staff will participate in the collection of data or otherwise have contact with the participants. Drexel will store all the data, and CDC will only receive coded and aggregated data so it will not be possible to link responses with individual subjects. Data will be treated in a secure manner and will not be disclosed, unless otherwise compelled by law.

Participants will be informed that providing information is voluntary. In addition, participants will be given an opportunity to consent to sharing and submitting information as shown in Attachments C, D, E, & F. In addition, assent will be obtained from all adolescent participants during enrollment, as shown in Attachment G. Adolescents under the age of 18 years, whose parents or legal guardians are not able to provide consent, will not be enrolled in the study.

Interviews will be conducted by members of the study team at Drexel. Surveys will also be administered by the study team at Drexel; study investigators and collaborating partners will email a link to the survey using Qualtrics. The survey data is housed on a secure server, and only study team members can access survey data. Information from both surveys and interviews will be maintained for the duration of the study, and available only to study team members for purposes of analysis. Printed documents containing personal information will be maintained in locked file cabinets when not in use, and digital information

will be maintained on password protected computer systems. Personal information will be destroyed after the study concludes.

A system of records is not being created for this study.

11. Institutional Review Board (IRB) and Justification for Sensitive Questions

Drexel has received IRB approval to conduct human research for this project through their institution’s IRB (see Attachment I). This research will not produce generalizable data. OPHPR OMB/PRA Coordinator determined no other IRB approval is needed.

The purpose of this study is to understand the communication needs of families with children who have special health care concerns, including autism spectrum disorders, during emergencies and disasters that threaten their health and safety. These communication needs may differ for families with different health issues. To capture the unique needs that families of diverse backgrounds and varied medical problems, we include potentially sensitive questions on both the surveys and the interviews.

12. Estimates of Annualized Burden Hours and Costs

The annualized response burden is estimated at 419 hours. Respondents will include families/caregivers, providers, emergency response professionals, and Health IT experts. See Exhibit 1 below for breakdown of time estimates for each type of data collection (survey, interview, focus group). Data collection will occur one time. Time estimates for the surveys are based on pilot test results, whereas time estimates of the qualitative protocols are based on previous work done by co-investigators with the same populations.

Exhibit 1: Estimated Annualized Burden Hours

Type of Respondent	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours
Families/Caregivers	Attachment J - CYSHCN Family/Caregiver Survey	150	1	15/60	38
Families/Caregivers	Attachment K - ASD Family/Caregiver Survey	200	1	15/60	50
Providers	Attachment L - CYSHCN Provider Survey	250	1	15/60	63
Providers	Attachment M - ASD Provider Survey	150	1	15/60	38
Families/Caregivers	Attachments N - CYSHCN Family/Caregiver Interviews*	50	1	1	50
Families/Caregivers	Attachment O - ASD Family/Caregiver Interviews*	30	1	1	30
Families/Caregivers	Attachment P - CYSHCN	30	1	90/60	45

	& ASD Family/Caregiver Evaluation Focus Group				
Providers	Attachment Q – CYSHCN Provider Focus Group	20	1	90/60	30
Providers	Attachment R – ASD Provider Focus Group	10	1	90/60	15
Emergency Response Organizations	Attachment S – Emergency Response Focus Group	10	1	90/60	15
Health IT Professionals	Attachment T – Health IT Focus Group	10	1	90/60	15
Providers	Attachment U – Provider Evaluation Focus Group	20	1	90/60	30
Total Burden = 419 hours					

*Includes Pre-Interview survey (Attachment V) which is included in burden estimate for the interviews.

Exhibit 2 shows the estimated annualized costs of the data collection activities described above. From Exhibit 2 the total estimated annualized burden cost of data collection for this study is \$24,943.77. The hourly rates were based on data from the Bureau of Labor Statistics¹. Given the diversity of occupations expected among the family/caregiver group, that group’s hourly wage of \$23.86 was determined by using the mean hourly wage across all occupations. The hourly wage for Emergency Response Organizations was based on the mean hourly wage for “Emergency Management Directors,” and the rate for providers was based on the mean hourly wage for “Physicians and Surgeons.” We used the same hourly wage for the Health IT and provider groups as we expect that many of the Health IT participants will be providers themselves.

Exhibit 2: Estimated Annualized Burden Costs

Type of Respondent	Form Name	Total Burden Hours	Hourly Wage Rate*	Total Respondent Costs
Families/Caregivers	Attachment J - CYSHCN Family/Caregiver Survey	38	\$23.86	\$906.68
Families/Caregivers	Attachment K – ASD Family/Caregiver Survey	50	\$23.86	\$1,193.00
Providers	Attachment L - CYSHCN Provider Survey	63	\$101.04	\$6,365.52
Providers	Attachment M – ASD Provider Survey	38	\$101.04	\$3,839.52
Families/Caregivers	Attachments N – CYSHCN Family/Caregiver Interviews*	50	\$23.86	\$1,193.00
Families/Caregivers	Attachment O – ASD Family/Caregiver Interviews*	30	\$23.86	\$715.80
Families/Caregivers	Attachment P – CYSHCN & ASD Family/Caregiver	45	\$23.86	\$1,073.70

	Evaluation Focus Group			
Providers	Attachment Q – CYSHCN Provider Focus Group	30	\$101.04	\$3,031.20
Providers	Attachment R – ASD Provider Focus Group	15	\$101.04	\$1,515.60
Emergency Response Organizations	Attachment S – Emergency Response Focus Group	15	\$37.53	\$562.95
Health IT Professionals	Attachment T – Health IT Focus Group	15	\$101.04	\$1,515.60
Providers	Attachment U – Provider Evaluation Focus Group	30	\$101.04	\$3,031.20
Total Respondent Costs: \$24,943.77				

* Includes Pre-Interview survey (Attachment V) which is included in burden estimate for the interviews.

1. National Occupational Employment and Wage Estimates in The United States, 2016. U.S. Department of Labor, Bureau of Labor Statistics. Division of Occupational Employment Statistics.

13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers

There are no other cost burdens to respondents and record keepers for this data collection.

14. Annualized Cost to the Federal Government

No CDC staff will be involved in the recruitment of respondents or any data collection. The average annual total cost of data collection by the contractors is \$382,619 for the three-year contract period.

15. Explanation for Program Changes or Adjustments

This is a new data collection.

16. Plans for Tabulation and Publication and Project Time Schedule

Exhibit 3 illustrates the timeline for activities related to this collection, including recruitment of participants, data collection, data analysis, and publication.

Exhibit 3. Project Timeline

Activity	Time Schedule
Recruitment	1- months after OMB approval
Data Collection	
a. Survey	1-2 months after OMB approval
b. Interviews	3-9 months after OMB approval
c. Focus Groups	6-9 months after OMB approval
Data Analysis	
a. Survey	3 months after OMB approval
b. Interviews	6-12 months after OMB approval
c. Focus Groups	6-12 months after OMB approval
Development of emergency communication tools and messages	18-22 months after OMB approval

Validation/Message testing	22-23 months after OMB approval
Publication	22 months after OMB approval

Note: Attachments W-Z include recruitment scripts for qualitative data collection. See Supporting Statement Part B for detailed information on recruitment strategies.

17. Reason(s) Display of OMB Expiration Date is Inappropriate

The display of the OMB expiration date is not inappropriate.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.