

November 20, 2017

Mr. Leroy A. Richardson
Information Collection Review Office,
Centers for Disease Control and Prevention
1600 Clifton Road NE., MS- D74
Atlanta, Georgia 30329

Re: Docket No. CDC-2017- 0071

Proposed information collection project titled “Effective Communication in Public Health Emergencies—Developing Community- Centered Tools for People with Special Health Care Needs.”

Dear Mr. Richardson,

Thank you for allowing comments regarding the potential project to collect information which would aide in caring for those with special needs during emergency situations. My comment is strictly personal and is not associated with either the law school which I attend nor the hospital system of my prior employment. Before entering law school, I worked in the Level One Trauma Center of Orlando Regional Medical Center and also spent this past summer as an intern with the Orlando Health Legal Affairs Department. Through my experiences, I have gained a thorough appreciation for what is involved in emergency and disaster situations. My main task in the Emergency Department was to work with the families of trauma victims. On the night of the Orlando Pulse shooting, one of my responsibilities was to move out stable patients and track where we moved them to make room for the critically injured victims. As a legal intern, I conducted research for my supervisor on the updated CMS rule for Emergency Preparedness. Because of these experiences, plus my undergraduate education in Molecular Biology and Microbiology and three semesters of law school, I am particularly concerned with the management of those with special health care needs during emergencies.

A. This proposed collection of information is necessary and will have practical utility.

This proposed project intends to target a specific population with unique needs: families with children and youth with special healthcare needs as well as individuals with Autism Spectrum Disorders and families with children who have Autism Spectrum Disorders. Based on United States Census reports for 2011-2012, 6% of children between the ages of three and five and 8.4% between the ages of six and twenty-one have diagnosed disabilities. Autism represents 7.2% of those disabilities. (<https://www2.ed.gov/fund/data/report/idea/partbspap/2013/fl-acc-stateprofile-11-12.pdf>). In city of Orlando, Florida, almost 30% of households have occupants under the age of eighteen. (<http://orlando.areaconnect.com/statistics.htm>). With that large of a number of citizens being affected, I have a very difficult time seeing how effective communication with the families of those with disabled children could be considered not incredibly important. In the United States alone, we see mass casualty incidents from severe weather, violence, terrorism, and more every time we turn on the news. Therefore, there needs to be a system in place to determine who needs adequate assistance in these circumstances. It is the duty of both the Office of Public Health Preparedness and Response and the Centers for Disease Control and Prevention to ensure the safety of these specific populations. With detailed information on who these families are and the extent of their needs, these departments can better fulfill their duties to them.

B. Ways to enhance the quality, utility, and burden of the proposed collection of information.

This proposal has already highlighted an important tool which modern healthcare providers have to contact families with specialized needs. As opposed to paper mail through the postal system, data collection can be conducted through an online portal set up for the purpose of providers filling out this survey. I firmly believe that health information protection issues can be

avoided by offering surveys to families directly as advertised by their providers. If healthcare providers are willing to direct their patients to an online survey to assess their needs, agencies involved can have an automatically processed way to collect and analyze this data. Therefore, the quality and the utility of the data can be increased by offering an additional survey to families themselves. Providers will be able to give useful information, however, there is only so much they can do with the limited personal knowledge they have of their patient families. By offering the survey to families themselves, the agencies can ensure accuracy and reliability of the data received.

Moving beyond the healthcare providers, the survey can be offered through advertising means such as social media or email. By partnering with special needs groups, the agencies can collect the email information of families who are registered with the groups and the survey can be dispersed through email. Many special needs groups operate through social media platforms, such as Facebook, as well. The groups can share the survey on their group pages to increase the reachability. I believe that the added component of direct family response will only minimally affect the burden of information collection, as most of the collection will be automated and with the help of special needs groups.

By having a survey which collects information directly from patients and patient families with special needs, one of the questions asked could collect contact information for family member such as phone/email. With that information, patients and families could have the opportunity to enroll in notification programs. The agencies could send out warnings and information specific to their special needs, by organizing the warnings by category of needs, and send the information directly to those affected. The notifications could be as simple as a directive for them to contact their healthcare provider or report to a certain shelter. These notifications

would, admittedly, add to the burden of the agencies, but with the mitigating benefit of an organized response.

In conclusion, with the information taken from patients and patient families, individuals can be directed to providers who specialize in their specific needs during an emergency. By sending out a text message to a family letting them know what is happening, identifying who they need to contact, or advising them on where to go and what to bring could be lifesaving. The burden of collecting this information could be greatly reduced by partnering with special needs organizations with directories of participating families as well as social media platforms. If healthcare providers work alongside the agencies to promote participation in the survey and subsequent study, patients and patient families would be more likely to trust that their information is secure and being used for their benefit. Costs can also be reduced by using a patient portal online to conduct the surveys and from there identifying who needs to be, or should be, interviewed. I believe that the hour burden of 419 hours should be increased to at least 500 hours to accommodate the data processing and interview time. However, the request of 24 months should be sufficient.

Sincerely,

Kelsey Weiss
Candidate for Juris Doctor 2019
Stetson University College of Law