NACIDD National Advisory Committee on Individuals with Disabilities and Disasters

Recommendations from the National Advisory Committee on Individuals with Disabilities and Disasters

DRAFT VERSION FOR PUBLIC REVIEW

This document will be reviewed and finalized during the NACIDD Public Meeting on April 20, 2023.

Those interested in attending the meeting may pre-register. Please see the agenda and registration link on the website

Ahead of the meeting, written comments may be submitted to NACIDD@hhs.gov.

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Introduction and Method of Work

The National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD or the Committee), was authorized by Congress in 2019.[1] The Committee has a charter to provide advice and consultation to the Secretary of the U.S. Department of Health and Human Services (HHS) and, per delegation of authority, the Assistant Secretary for Preparedness and Response to assist them in carrying out HHS responsibilities as they pertain to the specific needs of individuals with disabilities in preparation for, response to, and recovery from all-hazards emergencies and disasters. The NACIDD was inaugurated on March 30, 2022. The NACIDD is governed by the provisions of the Federal Advisory Committee Act (FACA) which sets forth standards for the formation and use of advisory committees. For the purposes of the charter and the work of the NACIDD, the term "disability" has the meaning given in 42 U.S. Code §12102.

The NACIDD is comprised of seven non-federal members, as required by Congress, selected from among subject matter experts who applied through a public announcement in the Federal Register. Those individuals have been appointed by the Secretary of HHS ("the Secretary") as Special Government Employees and are the voting members of the NACIDD. The NACIDD is also comprised of 10 federal, non-voting members who are *ex officio* representatives from agencies within HHS and other Executive Branch agencies. A full roster for the NACIDD is Appendix 1 of this report. Following the inaugural meeting, the voting members of the NACIDD elected Ms. Marcie Roth to serve as the chairperson.

Since its inauguration, the NACIDD formed four working groups to conduct the work of drafting recommendations. Those working groups—Training Working Group, Emergency Support Function (ESF) #6 and #8 Working Group, Compliance and Enforcement Working Group, and Effective Communication Access Working Group—met regularly throughout the second half of 2022 and the first quarter of 2023. The working groups then developed a first round of recommendations, which were proposed to the full committee for review in this draft report. Consistent with standard procedures for the National Advisory Committee (NAC) Program in the Administration for Strategic Preparedness and Response (ASPR), the voting members are responsible for drafting recommendations, considering advice from *ex officio* representatives and other subject matter experts. The draft recommendations are published on the ASPR NACIDD website for public review and discussion prior to a final vote.

In developing this first set of recommendations, the working groups held numerous meetings with federal and non-federal subject matter experts in a variety of disciplines. The Committee recognizes that future recommendations will be needed to address the many areas of concern, and members will continue to work with subject matter experts on developing additional

[1] The NACIDD is required by section 2811C of the Public Health Service Act (42 U.S.C. § 300hh-10d), as amended, by the Pandemic and All-Hazards Preparedness and Advancing Innovation Act (PAHPAIA), Public Law No. 116-22.

recommendations in subsequent reports to address issues impacting the health, safety, and independence of people with disabilities impacted by disasters.

Findings and Recommendations

In this report, the NACIDD is making several over-arching recommendations related to the observed gaps in response activities, including data-sharing and communication access during a disaster, and on the types of training required to address the needs of people with disabilities before, during, and after a disaster. In general, the NACIDD is concerned about the impacts of losing certain flexibilities that have been afforded under the COVID-19 public health emergency (PHE) declaration, which expires on May 11, 2023. The Committee is making several high priority recommendations in this first report based on the many documented experiences of people with disabilities who were impacted by emergencies during federally declared disasters, including but not limited to the COVID-19 pandemic. In advance of a future PHE declaration, the Committee believes these recommendations are relevant for individuals who are responsible for compliance with federal disability civil rights laws, including obligations for disability inclusion, equity, and accessibility in public health emergency preparedness, response, recovery, and mitigation in the United States.

Additionally, the Committee members remain concerned that the NACIDD will be forced to terminate unless extended by Congress. A timely extension prior to September 30, 2023, will enable the NACIDD to move forward in a meaningful way to reach the goals outlined in its authorizing legislation. Concurrent with the extension of the NACIDD, committee members encourage the Secretary and ASPR to expand the capacity and diversity of the Committee by identifying and involving additional subject matter experts.

1. Review and remediate HHS's use of blanket waivers under Section 1135 of the Social Security Act to ensure appropriate care and legal protections during PHEs.

The NACIDD is concerned about the use of Section 1135 blanket waivers and Section 1812(f) flexibilities granted by the Centers for Medicare and Medicaid Services (CMS) during PHEs and other federally declared disasters. During emergencies, these waivers can result in people with disabilities being transferred from their home, emergency room, shelter, or hospital bed into a skilled nursing facility or other congregate setting, without a plan to return these individuals back to their communities. The use of these waivers to institutionalize people during disasters may result in segregation that is prohibited by the Americans with Disabilities Act (ADA, P. L. 101-336), the 1999 Supreme Court decision held in Olmstead v. L.C., the Rehabilitation Act (P. L. 93-112), as amended, and other disability civil rights laws. Despite HHS and Department of Justice (DOJ) statutory prohibitions on waivers to civil rights protections, the use of 1135 blanket waivers and 1812(f) flexibilities during emergencies results in individuals being institutionalized, and often trapped, in congregate facilities. States are responsible for collecting the data on people who are in institutions; however, when requirements are waived during disasters, states

lose visibility on who is entering institutions and there is no effective mechanism for collecting specific data. People tend to get "lost" in the system even when there are no waivers in place. The specific data points that should be included in reviewing the use of these authorities are: 1) who are the people institutionalized because of a disaster, 2) how long have they been in the institution, and 3) what steps is each institution/state taking to move individuals back to their communities with the supports they need.

The NACIDD recommends that the Secretary direct CMS and the HHS Office for Civil Rights (and any other decision-making bodies, like the Health Resources and Services Administration) to jointly review the use of waivers under Section 1135 of the Social Security Act in PHEs, and determine a remediation strategy that encourages state and local governments to prevent the institutionalization of and, when necessary, expeditiously return people with disabilities to their homes during an emergency. Independent and community living support and services need to be in place so people with disabilities can live in the most integrated setting appropriate to their needs.

2. Provide the members of the National Advisory Committee on Individuals with Disabilities with the HHS Secretary's Operations Center briefing updates during its activation in a response.

Having access to real-time public health emergency data and activities from the Secretary's Operations Center (SOC) during an HHS response activation would provide the NACIDD with a more accurate picture of the gaps that occur throughout federal response operations. Observation and identification of these gaps will assist the committee in forming a basis for advising the Secretary through recommendations, findings, and reports that could be voted on during public meetings. The NACIDD recommends that the Secretary support its access to the data reported through the SOC.

3. Include timely development and distribution of native sign language videos, information in plain and easy to understand language, and Limited English Proficiency products during a PHE to provide equally effective communication access.

The NACIDD has found that when public health guidance is distributed to the public on issues and actions that concern their immediate wellbeing and health, information may not be accompanied by native sign language videos and other auxiliary aids and services. Such messages fail to use plain language, easy to understand content, and products for Limited English Proficiency (LEP). HHS is obligated to meet all effective communication, LEP, and plain language requirements under Sections 504 and 508 of the Rehabilitation Act of 1973, as amended, Title VI of the Civil Rights Act of 1964, and the Plain Writing Act of 2010 respectively.

Native sign language is a distinct language and is not a simple conversion of written English or other spoken language. The absence of native sign language limits equally effective

communication access for individuals whose first language is not English or other spoken language and may limit understanding of guidance when only provided these forms of communication. Individuals with intellectual and developmental disabilities also may experience barriers to effective communication access. These limitations in access to effective communication are even more pronounced in a PHE when people need to be alerted on critical information to help them better prepare before, during, and after a disaster.

As not all audiences seek out information online or through text, HHS would have greater impact by increasing engagement with its partner organizations that serve people with disabilities, older adults, and LEP communities. Examples include providing health information in braille, large print materials, as well as other alternative formats that use plain language. This approach would be effective in assisting state agencies serving individuals who are deaf, hard of hearing, blind, or have low vision.

The Committee recommends that the Secretary allocate funding and issue clear directives regarding processes, procedures, protocols, policies, and training for developing timely products that reach a broader audience when providing information and actions related to preparing for, responding to, and recovering from a PHE or disaster.

4. **Develop and require brief, just-in-time, and regular refresher training for disaster response personnel and partner volunteers on the disaster-related accessibility, equity, inclusion, and health maintenance needs of people with disabilities and their requirements for complying with all applicable disability laws.**

The NACIDD recommends that HHS develop, in consultation with subject matter experts with disaster response and disability knowledge, brief training modules for disability accessibility, equity, inclusion, and health maintenance that can be used "just-in-time", for people who have not been fully trained or as refresher training. Additionally, HHS should require such training for all staff and volunteers who work with the public prior to the beginning of their first shift, as well as for staff and volunteers who develop operations protocols during an active response operation. The Committee suggests the Secretary explore resources to train responders in the U.S. Public Health Service Commissioned Corps, the National Disaster Medical System, the Medical Reserve Corps, and others who are regularly deployed, who must be able to meet the disaster-related disability accommodations and health needs of people with disabilities.

These modules should be available in advance of response activities and should be developed in a format that is easily received, actionable, and based on the commonalities encountered by people with disabilities across all hazards. Note that for the purposes of this recommendation, just-in-time training means providing high level awareness necessary to meet assigned tasks during a disaster operation that can be delivered quickly to a wide variety of responders. These training modules should be developed in non-disaster times as not to be ad-hoc in nature.

5. **Establish grants for disaster mental health training for clinicians and non-clinical professionals in the health system that address the specific lived experience of people with disabilities.**

Consistent with the recommendations recently issued by the National Advisory Committee on Children and Disasters, the NACIDD recommends identification of funding for HHS grants to train health care staff members, especially healthcare staff members with lived disability experience, in disaster mental health for people with disabilities, including training related to trauma, grief, and loss. This should include specialized training for interpreters for deaf, hard of hearing, and deafblind as well as LEP. The goal should be to incorporate the needs of multiple populations as HHS supports the building of system-wide capacity for the mental health system and broader community. The NACIDD encourages the Secretary to explore additional funding streams for these grants to avoid siloing such programs within limited populations.

Appendix 1: Committee Roster

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