U.S. Department of Health & Human Services
Administration for Strategic Preparedness and Response

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

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Contents

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 working groups to conduct the work of drafting recommendations. The working groups focused on four key areas including training, Emergency Support Function (ESF) #6 and #8, compliance and enforcement, and effective communication access. The working groups 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 observed gaps in response activities, including recommendations on data-sharing and communication access during a disaster, and 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 afforded under the COVID-19 public health emergency (PHE) declaration, which expired on May 11, 2023. The Committee's high priority recommendations are 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. These recommendations are relevant to individuals responsible for compliance with federal disability civil rights laws, and who have obligations for disability inclusion, equity, and accessibility in PHE preparedness, response, recovery, and mitigation in the United States.

Additionally, the Committee remains concerned that the NACIDD will be forced to terminate unless extended by Congress. A timely extension prior to September 30, 2023, would enable the NACIDD to move forward 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 appointing additional subject matter experts.

1. Review and correct 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 recommends removal of certain provisions of section 1135 waivers of the Social Security Act, including flexibilities for preadmission screening and annual resident review (PASRR), the placement of people in congregate settings, and minimum data set authorizations and other data collection. The NACIDD rejects the use of these provisions under the 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 homes, emergency rooms, shelters, or hospital beds into skilled nursing facilities or other congregate care settings, 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 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 care facilities. States are responsible for collecting 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 these 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 at minimum:

1) Who are the people institutionalized because of a disaster?
2) How long have they been in the institution?
3) What steps is each institution/state taking to move individuals back to their communities with the supports they need?

State and local governments must adhere to all legal and civil rights obligations. The NACIDD recommends that this be accomplished by the Secretary directing CMS and the HHS Office for Civil Rights (and any other decision-making bodies, like the Health Resources and Services Administration) to jointly conduct a review of the use of 1135 waivers in PHEs and enforce immediate corrective actions to meet state and local government requirements under federal law to actively prevent and remediate the institutionalization of people with disabilities. This review must include documentation of continual monitoring and enforcement of civil rights laws and disability rules, regulations, and policies. Remediation must include the expeditious return of people with disabilities to their homes or other non-congregate temporary and long-term disaster housing during and following an emergency. Independent and community living support and services must be in place so people with disabilities can live in the most integrated setting appropriate to their needs. Policy and training must reflect this change in the use of1135 waivers.

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

Having access to real-time data and information on 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 videos, press releases, press conferences, and all other communication in American Sign Language and regional or locally used sign languages appropriate for the populations affected by a PHE. All communication must be in plain and easy to understand language, and produced for people with Limited English Proficiency before, during, and after an emergency to provide equally effective communication access.**

The Secretary must issue clear directives regarding processes, procedures, protocols, policies, and training for the development of timely products that reach a broad audience when providing information and actions related to preparing for, responding to, and recovering from a declared—or not officially declared—PHE or disaster.

The NACIDD has found that when health guidance is distributed to the public on issues and actions that concern their immediate wellbeing, information may not be accompanied by American Sign Language (ASL) and regional or locally used[2] sign language videos and other auxiliary aids and services. Such messages may also fail to use plain language, contain easy to understand content, or be suitable products for people with Limited English Proficiency (LEP). HHS is obligated to meet all effective communication guidance requirements, as mandated by the Americans with Disabilities Act (ADA, P. L. 101-336), Sections 504 and 508 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and the Plain Writing Act of 2010 respectively.

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 to provide 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, deafblind, people who have low vision, people who are blind, or people with intellectual and developmental disabilities.

4. **Develop, require, and frequently update brief just-in-time training for all PHE responders on disaster-related accessibility, equity, inclusion, and health maintenance needs of people with disabilities, and the requirement for compliance with all applicable disability laws.**

Note that for the purposes of this recommendation, just-in-time training means providing actionable competencies to meet assigned tasks during a disaster operation that can be

[2] A regional or locally used sign language is a distinct language appropriate to the location affected and is not a simple conversion of written English or other spoken language. The absence of regional or locally used 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. Individuals with intellectual and developmental disabilities also may experience barriers to effective communication access.

delivered quickly to all responders. This type of training prevents random and inconsistent delivery and development of content.

The NACIDD recommends that HHS develop and maintain as current—in consultation with disaster response and disability inclusion experts—brief training modules for disability accessibility, equity, inclusion, and health maintenance that can be taken "just-in-time" by all personnel who work with the public and those who develop protocols during an active response operation. Training should be taken prior to the beginning of employees' and volunteers' first shift.

The Committee recommends that HHS develop or provide resources to train responders including the U.S. Public Health Service Commissioned Corps, the National Disaster Medical System, the Medical Reserve Corps, and others who are regularly deployed and who must be able to meet the disaster-related accommodations and health needs of people with disabilities and others with access and functional needs.

These modules should be developed in a consistent format that is easily received, actionable, and based on the civil rights compliance requirements.

Appendix 1: Committee Roster

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