National Advisory Committee on Seniors and Disasters and National Advisory Committee on Individuals with Disabilities and Disaster Joint Public Meeting

Meeting Summary September 19, 2023 1:00 – 3:00pm (Virtual)

Roll Call

NACSD Voting Members

- Dr. Gregory Santa Maria (Chair)
- Dr. Sue Anne Bell
- Dr. Lisa M. Brown
- Deborah Dalpoas-Ward
- Maria Greene
- Dr. Mary Russell

NACSD Ex Officio Members

- Dr. Daniel Dodgen, Administration for Strategic Preparedness and Response (ASPR)
- Derek Lee, Administration for Community Living (ACL)
- Mr. Benjamin Olivari, Centers for Disease Control and Prevention (CDC)
- Dr. Emerald Nguyen, National Institutes for Health (NIH)
- Maggie Jarry, Substance Abuse and Mental Health Services Administration (SAMHSA)
- Leslie Saucedo, U.S. Department of Homeland Security
- Kevin Thompson, U.S. Department of Veterans Affairs

NACSD Subject Matter Experts

- Dr. Michael Wasserman
- Dr. Anna Fisher

James Robinson

NACIDD Voting Members

- Marcie Roth (Chair)
- Vicky Davidson
- Elizabeth A. Davis
- Julie Foster Hagan
- Barbara L. Kornblau
- Donna Platt

NACIDD Ex Officio Members

- Darrin Donato, ASPR
- Kathleen Votava, ACL
- Amy Nicholas, National Council on Disability
- Tim Creagan, U.S. Access Board
- Sherman Gillums, Jr, U.S. Department of Homeland Security
- Dr. Karyl Rattay, (CDC)

NACIDD Subject Matter Experts

- Dr. Rosanne Rushing
- Christine Woodell

ASPR Staff

- Dr. Maxine Kellman
- Tabinda Burney
- LCDR Cliffon Smith
- Zhoowan Jackson
- Laura Gardiner
- Megan Hoffmann
- Mariya Dimitrova

Overview

The National Advisory Committee on Seniors and Disasters (NACSD) and the National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) met for a public meeting on September 19, 2023, to deliberate on two sets of recommendations for the Assistant Secretary of

Preparedness and Response and for the Secretary of Health and Human Services. The Committees' public meeting had over 360 registered participants. The NACSD and NACIDD are Federal Advisory Committees that provide advice and guidance to the Assistant Secretary for Preparedness and Response within the U.S. Department of Health and Human Services (HHS), and to the HHS Secretary. The Committees provide expert advice and guidance to enhance all-hazards public health and medical preparedness, response, and recovery to meets the needs of older adults and their families and individuals with disabilities, respectively.

Opening Remarks

Dr. Maxine Kellman, the Designated Federal Official for the NACSD, opened the public meeting with an overview of Federal Advisory Committee Act (FACA) requirements and rules of engagement for the meeting.

NACSD Welcome Remarks

Chairperson Dr. Gregory Santa Maria made introductory remarks thanking the committee members and the participating public for their input. Dr. Santa Maria discussed the importance of the committee and its working groups. Dr. Santa Maria introduced Dr. Sue Anne Bell, Co-Chair of the NACSD Infrastructure Working Group to read the Committee's recommendations.

NACSD Recommendations

Dr. Sue Anne Bell read the Committee's recommendations. All recommendations were voted on and approved by quorum of the Committee.

1) HHS should seek funding through the Older Americans Act Title VII for an Office of State Long Term Care Ombudsman Program to:

- a) Develop an emergency preparedness training curriculum
- Develop and provide an emergency preparedness training curriculum targeted for teaching resident and family councils in long-term care facilities (LTCF) about emergency preparedness, response, and recovery
- c) Provide and require grant funding through HHS for emergency management and health coalitions to integrate advocates including representatives of the Long-Term Care Ombudsman program, into local coordination for disaster and health emergencies planning
- d) Support involvement in local/state/national situation briefings and updates on emergency incidents to provide appropriate advocacy
- e) Encourage State, Local, Tribal and Territorial emergency responders to include long-term care Ombudsman in their regularly scheduled prep meetings and drills related to issues of long-term care advocacy

2) HHS should create a Virtual Long Term Care Support & Guidance Center to:

- a) Develop and disseminate real-time expert-driven recommendations to LTCFs
- b) Provide all LTCFs with regular training, including drilling, on how to transition to an incident command management structure
- c) Provide support during a disaster, including pandemics and other public health emergencies, to assist local leadership teams in focusing on day-to-day management, transferring the responsibility of training, PPE procurement, engineering, testing, and real-time expert-driven recommendations to a centralized entity

The Committee recommends this be situated within one of the Disaster Care Centers of Excellence for Older Adults (DCOA).

- 3) HHS should create a National Medical Director Registry.
 - All nursing homes should be required to submit specified information on their medical director, including proof of, or progress toward, certification. The Registry would be available for Federal, State and Local Health Departments and Health Care Coalitions in order to improve communications before, during and after emergencies and disasters
- 4) HHS should convene a Long-Term Care Leadership and Management Training for Emergency and Disaster Preparedness and Response Commission.
 - a) Establish leadership and management standards for LTCFs
 - b) Make recommendations among HHS agencies including CMS, providing guidance to State Governments related to oversight of LTCFs in relation to leadership and management competencies
 - c) The commission should be comprised of a majority of experts with pertinent competencies in geriatrics and gerontology (physicians, nurse practitioners, physician assistants, psychologists, pharmacists, social workers, physical, occupational and speech therapists, dieticians) and a representative from either a state long-term care ombudsman program or the national long-term care ombudsman program coordinator
- 5) HHS should develop supports and technical guidance for long-term care settings to plan for and implement climate resilience strategies that support patients, staff, and families.
 - a) Develop strategies and training for the direct care workforce to be climate resilient
 - b) Require LTCFs participating in CMS programs to have plans to incorporate renewable energy by 2030
- 6) Centers for Medicare and Medicaid Services (CMS) should amend the emergency preparedness rule to require planning for long-term heat and cold emergencies.
 - a) Require LTCFs to have plans for emergency power to maintain adequate temperature control
- 7) HHS should improve equity across the disaster management cycle for older adults:
 - a) Improve current procedures for resource sharing and mutual aid in low-resource settings
 - b) Develop training programs for healthcare providers to address issues with vulnerable older adults and emergency planning as part of routine health promotion activities
 - c) Develop online training modules for disaster health responders specific to disaster care for older adults
- 8) HHS should develop and provide emergency preparedness training curriculum targeted at healthcare providers in Indian Health Service training programs focused on the health and wellbeing of older adults in relation to preparedness, response, and recovery after emergencies.
 - a) This training should be developed and coordinated with the communities being served to ensure the information is culturally appropriate to the communities' traditional beliefs

Public Comment

The NACSD received a written comment from Elizabeth Gould, MSW, LCSW, Co-Director and Senior Research Public Health Analyst at the National Alzheimer's and Dementia Resource Center, sharing the Emergency Preparedness Toolkit for People Living with Dementia developed by the Center, funded by the Administration on Aging/Administration for Community Living.

Marina Lent, a Health Agent at the Aquinnah Board of Health submitted a written comment about the challenges of ensuing ongoing access to medications beyond "just-in-time" deliveries to local pharmacies or shipping directly to homes, particularly for less populated and remote areas. Ms. Lent was particularly interested in predicting how many people may need access to psychotropic medications during disaster recovery. Additionally, this comment inquired about best practices to manage a shelter population in the face of the severe emotional stresses during recovery to a major, destructive disaster.

The Chairperson thanked Ms. Lent for her comment and will follow up off-line.

NACIDD Remarks

NACIDD Welcome Remarks

Chairperson Ms. Marcie Roth made introductory remarks thanking the Committee members and the participating public for their input. The Chairperson also thanked the ASPR National Advisory Committee program staff, and especially the members of the NACIDD for their work and dedication.

NACIDD Recommendations

Ms. Marcie Roth read the Committee's recommendations. All recommendations were voted on and approved by quorum of the Committee.

- 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.
 - a) Removal of certain provisions of the Section 1135 waivers of the Social Security Act
 - b) Prevent people with disabilities from being transferred from home to other facilities without a plan to return them to their communities
 - c) Prevent segregation of people with disabilities within congregate settings during a disaster
 - d) Enforce state and local government adherence to all legal and civil rights obligations
- 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 response.
 - Real-time access to data and information from the Secretary's Operations Center (SOC) to provide more accurate picture of activities and gaps
 - b) Identify gaps to form basis for advising Secretary on future activities
- 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.

- 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 applicable disability laws.
 - a) Develop and maintain current brief training modules
 - b) Train responders who are regularly deployed

Public Comment
No public comments received.

Final Remarks

Remarks from Dr. Santa Maria, delivered as a private citizen:

Secondary to Congressional goals, our committee is going to be sunset. Our work is going to be put in the National Archives - we would not have volunteered our time if we knew this would be the outcome. The self-serving interest of the politicians who authorized our committee to protect the needs of people who need to be protected the most has resulted in a delay in our work.

Dr. Santa Maria also read the following statement:

The right to vote is one of the most significant rights we as Americans are afforded. We vote for representatives that we expect to serve our needs and represent us, the people they work for.

The NACSD is a congressionally authorized committee that has been identified to sunset on September 30th of this year. NACSD has asked Congress for reauthorization and was expecting that result prior to the sunset date. Unfortunately, secondary to their own goals, and not those protective of the American people, congressional reauthorization will not occur in time for the committee to resume its work, and now that work will be placed on an indefinite hold. While we have been advised that our work will ultimately wind up in the national archives, that was not our goal. Our goal was to get our work into the hands of planners and responders, where it will be used to create safer spaces for Americans in disaster.

This all occurs while the world is seeing an exponential increase in disasters, putting the very people congress authorized our committee to protect in unnecessary danger. The delay of our work is an unacceptable result of the self-serving interests of those elected to serve us, those who I believe have forgotten what the word service to the country means. It is my opinion as a private citizen, and one who understands the role of our government, that this action is not in the spirit of what our country was built on and is a slap in the face to everyone who has worked so hard on this, and other initiatives designed to safeguard the most vulnerable of American people in times of crisis.

I hope that Congress can rise above this and get back to this important work.

Thank you

Remarks from Ms. Roth, NACIDD Chairperson:

The Chair stated she has long supported a committee led by people with disabilities about emergency preparedness inclusive of people with disabilities. Was excited by committee focused on 27% of the US adult population. We need to center the rights and needs of people with disabilities, who account for 27% of the population, in all aspects of public health. Since our first meeting, about 18 months ago, 10 states have had a declared public health emergency and 3 national PHEs. There have been 97 major disaster declarations, 23 of these have each exceeded 1 billion in losses. The impact on people with disabilities are incalculable, many people with disabilities have died and many have been institutionalized. Billions of dollars have been granted, yet our committee has yet to identify any consistent monitoring or enforcement actions to protect people with disabilities. The deaths of hundreds of thousands of people with disabilities are continuing today. The NACIDD and two other committees will sunset in 11 days to due to expiration of

PAHPA. The inaction of Congress and the failure of our elected officials to prioritize public health and a piece of legislation whose first word is pandemic, while we are navigating impact of pandemic, has gotten us here. We can't get legislation in place that addresses pandemics and all hazards and protects all people. I wish our work was taken more seriously by decision-makers; and I can say with confidence that we will be persistent in our commitment to improving outcomes for people with disabilities, older adults, children, and others with access and functional needs.

Adjournment

Dr. Maxine Kellman adjourned the public meeting at 1:58pm Eastern Time.