National Advisory Committee on Individuals with Disabilities and Disasters National Advisory Committee on Seniors and Disasters

National Advisory Committee on Seniors and Disasters (NACSD) and National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) Public Meeting Summary

August 4, 2022 Location. Washington, DC (virtual) 2:00 pm – 4:00 pm

Attendees

NACSD Voting Members

Dr. Greg Santa Maria, Chair

Dr. Sue Anne Bell

Dr. Lisa Brown

Ms. Debbie Dalpoas-Ward

Ms. Maria Greene

Dr. Mary Russell

NACSD SMEs

Dr. Anna Fisher

Ms. Martha Morrison

Mr. James Robinson

Dr. Michael Wasserman

NACSD Ex Officio

Dr. Cheryl Levine, ASPR

Mr. Derek Lee, ACL

Mr. Deepak Agarwal, BARDA

Dr. Emerald Nguyen, NIH

Ms. Elizabeth Sadove, FDA

Mr. Eric Weakly, SAMHSA

Mr. Jason Lagria, DHS for Ms. Leslie Saucedo

Mr. Kevin Thompson, VA

NACIDD Voting Members

Ms. Marcie Roth, Chair

Ms. Vicky Davidson

Ms. Elizabeth Davis

Ms. Julie Foster Hagan

Ms. June Kailes

Ms. Barbara L. Kornblau

Ms. Donna Platt

NACIDD SMEs

Dr. Károly Mirnics

Dr. Rosanne Rushing

NACIDD Ex Officio Members

Dr. Cheryl Levine, ASPR

Ms. Jill Jacobs, ACL

Ms. Mercedes Rooks, BARDA

Ms. Blythe Ryerson, CDC

Ms. Elizabeth Sadove, FDA

Mr. Greg Fehribach, U.S. Access Board

Ms. Amy Nicholas, National Council on Disability

Mr. Jason Lagria, DHS

Designated Federal Officials

Dr. Maxine Kellman, NACSD DFO

Ms. Tabinda Burney, NACIDD DFO

Administration for Strategic Preparedness and Response

Dr. Meg Sullivan, Chief Medical Officer

RADM Theresa Lawrence

Dr. Kristin DeBord

Dr. Chris Hassell

Ms. Amelia Marlowe

Dr. Matt Sharkey

National Advisory Committee Team

Mr. Darrin Donato

Ms. Laura Gardiner

Ms. Mariam Haris

Ms. Megan Hoffmann

Ms. Zhoowan Jackson

CAPT Christopher Perdue

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Introduction

The National Advisory Committee on Seniors and Disasters (NACSD) and the National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) had a joint public meeting on August 4, 2022. The Committees provided status updates since their inaugural meeting and discussed their focus areas and top priorities as well as addressing public comments. Public comments are noted in Appendix 1. Over 420 people participated in this meeting.

The joint public meeting of the NACSD and the NACIDD is being held virtually. National Advisory committees are covered under the Federal Advisory Committee Act (FACA) (5 U.S.C. App.) and is the legal foundation defining how federal advisory committees operate. The law has special emphasis on open meetings, chartering, public involvement, and reporting. The NACSD and NACIDD are governed by the provisions of FACA. The National Advisory Committee on Seniors and Disaster is required by section 2811B of the Public Health Service Act (42 U.S.C. § 300hh-10c), as amended, by the Pandemic and All-Hazards Preparedness and Advancing Innovation Act (PAHPAIA), Public Law No. 116-22. The NACSD is governed by the provisions of the Federal Advisory Committee Act (FACA), Public Law 92-463, as amended (5 U.S.C. App.), which sets forth standards for the formation and use of advisory committees. The National Advisory Committee on Individuals with Disabilities and Disaster 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. The NACIDD is governed by the provisions of the Federal Advisory Committee Act (FACA), Public Law 92-463, as amended (5 U.S.C. App.), which sets forth standards for the formation and use of advisory committees. For the purposes of this charter and the work of the NACIDD, the term "disability" has the meaning given such term in 42 U.S. Code §12102.

Opening Remarks

Dr. Meg Sullivan, Chief Medical Officer, Department of Health and Human Services (HHS), Administration for Strategic Preparedness and Response (ASPR).

Dr. Meg Sullivan spoke on behalf of the Assistant Secretary for Preparedness and Response, Ms. Dawn O'Connell, who was unable to attend. The Administration for Strategic Preparedness and Response needs to respond to a wide range of health disasters from COVID-19 to monkeypox to flooding, ASPR is reminded each day that it is necessary to continuously improve responses. ASPR was recently elevated to an operational division by HHS Secretary Becerra. With this change the mission remains unchanged. The importance of the work also remains unchanged, and these committees will continue to play important roles for years to come. The federal government can only do its job with the help of state, local, tribal, and territorial (SLTT) partners. These committees are asked to use recommendations from COVID to bring recommendations for improvement back to HHS from SLTT partners.

Committee members are uniquely positioned to help ASPR improve. In recent weeks Dr. Sullivan spoke with all of the National Advisory Committees. It is clear that ASPR's goals are well aligned of the goals of committee members. ASPR is eager to hear feedback and examine how to continuously incorporate the committees' ideas into carrying out the mission.

National Advisory Committee on Seniors and Disasters (NACSD) Updates

Chairperson, Dr. Gregory Santa Maria, introduced the NACSD. The NACSD currently has four focus teams that include Behavioral Health, Infrastructure, Partnerships, and Communications. The committee has a special focus on disaster literacy and understanding disaster impact and inclusion and equity across the lines of effort underway by the NACSD. Each focus area considers mitigation, preparedness, response, and recovery in all aspects of health care which includes in-home and clinical. For each of the focus area voting members lead.

Behavioral Health, led by Dr. Lisa Brown, focuses on evaluating the use of current best practices in disaster behavioral health, implementation of evidence-based behavioral health practices, and behavioral health programs intended to benefit older adults and their families and caregivers in systems providing services at all stages of a disaster (e.g., mitigation, preparedness/readiness, response, and recovery) in all settings (e.g., long-term care, community-dwelling, homebound, and senior communities).

Focus Areas for Behavioral Health:

- Essential/non-essential designation of non-physician behavioral health clinicians
- State licensing regulations for interstate behavioral health clinicians during a disaster
- Telehealth
- Education, training, and utilization of a trauma-informed care approach and psychological first aid
- Options for addressing the dearth of applied research in the area of behavioral health and disasters

Communications, led by Ms. Maria Green, focuses on evaluating disaster, public health emergency systems' messaging, and relevant educational and resource materials to understand how older adults and adults with disabilities perceive, receive, and react to emergency messages. Their intent is improving emergency communications to reduce the occurrence of mis-, dis-, and mal-information, messaging before, during and after disaster events. The focus group will consider the following: disaster literacy, health literacy, equity, plain language, English Language Proficiency, and meet all legal requirements for accessibility.

Focus Areas for Communications:

- Disaster Literacy
- The inclusion of equity in Emergency Preparedness plans
- Mis-information, dis-information and mal-information
- Coded Levels of Emergency Messages
- Surveys of Emergency Management and Public Health Agencies
- Partner involvement in Messaging development, utilization of trusted sources
- Emergency Preparedness Grant Funding



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Infrastructure, co-led by Dr. Sue Anne Bell and Ms. Debbie Dalpoas-Ward, focuses on supporting mitigation, preparedness, response, and recovery for all older adults, and particularly across all aspects of long-term care. For the purposes of this report, long-term care is defined as older adults receiving supportive services at home, group homes, memory care, assisted living, and nursing homes.

Focus Areas for Infrastructure:

- Possible development of Centers of Excellence in Geriatric Disaster Management
- Long-term care workforce leadership training in emergency response
- Utilization and expansion of existing Long-Term Care Ombudsman Program resources
- Strategies for long-term care settings to build climate resilience

Partnerships, led by Dr. Mary Russell, focuses on Identifying local traditional and force-multiplier partnerships that can receive capacity building disaster competency training to promote community readiness and continuity of care services for older adults and can be coordinated and integrated into planning for emergency preparedness, response, and recovery efforts.

Focus Areas for Partnerships:

- Capacity building and disaster competency training for local traditional and force-multiplier partners in disaster preparedness and response
- Templates for disaster preparedness and response
- Disaster training resources for professionals and for the general population
- Identifying leads to coordinate and integrate planning for emergency preparedness, response, and recovery efforts for older adults
- Existing tools to identify at-risk persons, for state planners, emergency managers, older adult advocacy groups, and academic institutions
- Metrics to identify community progress toward disaster readiness and support evaluation after disaster incidents
- Inclusion of older adult agency participation in Healthcare Coalitions

National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) Updates

Chairperson, Ms. Marcie Roth, introduced the NACIDD. Since the inaugural meeting in March and April of 2022 the NACIDD has identified 54 priorities and has selected four key categories to be addressed along with leads for the four groups. The processes underway includes establishing working groups, determining priorities for each, establishing shared terminology, establishing timelines, and implementing accommodations for members. The four focus groups are Compliance and Enforcement, Emergency Support Functions 6 & 8, Training, and Effective Communication Access.

Compliance and Enforcement, led by Ms. Barbara Kornblau, focuses on aligning relevant civil rights laws, legal requirements, and regulations such as the Americans with Disabilities Act (ADA), the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act (IDEA), and the Stafford Act. The focus will be on making recommendations to ensure consistent monitoring and enforcement of these requirements at the federal, state, and local levels.

Focus Areas for Compliance and Enforcement:

- Provide disability inclusive emergency management expertise in each agency to advise directors on legal compliance obligations related to policy and practice requirements
- Enforce Rehabilitation Act and the Americans with Disabilities Act (ADA) Olmstead most integrated setting requirement in all public health emergencies and disasters

Emergency Support Functions 6 & 8 (ESF6 & 8), co-led by Ms. June Kailes and Ms. Vicky Davidson, focuses on providing and protecting the needs and rights of people with disabilities and their families and/or support networks through the facilitation of the people with disabilities' health, safety, and independence. As well as identifying and closing the gaps in the National Incident Management System/National Preparedness System.

Focus Areas for ESF 6 & 8:

- Conduct gap analysis of all emergency support functions
- Develop recommendations for closing identified gaps
- Resolve gaps created by existing Medicaid rules in crossing state lines before, during, and after disasters

Training, co-led by Ms. Elizabeth Davis and Ms. Julie Hagan, focuses on establishing a core methodology for training and resources for disaster emergency management regarding persons with disabilities, including a rubric that demonstrates how training must be accomplished and expected deliverables. This methodology would be utilized for educational needs across all recommended activities.

Focus Areas for Training:

Identify effective inclusive training and exercise guidance and methodologies currently in
practice across the federal, state, local, and tribal levels from which a comprehensive guide
agnostic to specific training goals, but specific to the process of developing and executing
knowledge transfer can be developed and disseminated

• Ensure that federal mandates require utilization of the training and exercise guide as part of all training measures and funding support, thus infusing inclusivity across all relevant topic areas

Effective Communication Access, led by Ms. Donna Platt, focuses on identifying the issues of communication access in the areas of medical preparedness, response, and recovery including through emergency alerts, emergency information and materials, healthcare communications, and telehealth services. Recommendations and resources will be developed to prepare and assist responders to help ensure that individuals who are deaf, hard of hearing, deafblind, blind and/or have low vision, speech disabilities, and other disabilities have equal access to information and services to protect their health and well-being before, during, and after all-hazards public health events.

Focus Areas for Effective Communication Access:

- Ensure alerts, warnings, emergency notifications, and all digital communications are actionable and equally accessible at all times
- Ensure that the distribution of public health and emergency materials are available to people with disabilities with accessible and actionable instructions that are written in plain language

NACSD and NACIDD Discussion on Crosscutting Issues

Communications:

Members stated that communications—including getting materials to the end users that need them—have always been among the biggest issues in preparedness, mitigation, and post-event notification. The committees are reviewing mechanisms and partnerships to reach key audiences. The Committees may want to recommend adding new requirements for the Hospital Preparedness Program where healthcare coalitions could be utilized for messaging. Committees may discuss the development of an overarching communication strategy that reaches all groups.

Telehealth:

Members from both committees shared that telehealth is an important issue for both people with disabilities and for older adults. Members of the NACIDD noted that telehealth for people with disabilities was very difficult during COVID-19 because there were technology gaps that did not address their need. For example, American Sign Language interpreters or real-time captioning wasn't available for people who needed it. Accommodations for non-native English speakers bring up similar gaps and issues. The National Institute for the Deaf has produced a report on gaps in telehealth capacity for the deaf. The organization is also setting up guidelines for telehealth providers to improve access for the deaf.

An NACSD member detailed that long-term care facilities are home to approximately two million Americans and many of these facilities aren't equipped for telehealth and many residents don't have smartphones. Staff spend their limited time facilitating the use of basic technology as telehealth often includes hurdles that the elderly may not be able to surmount. The opportunity for all groups to use telehealth keeps people out of the emergency care system. Members concurred and stated that there



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are also communications issues during disaster management, as well as connectivity and equipment related problems. The committees must deliberate the need for communications access, interpreters, close-captioners, technical support, and connectivity. Members noted that if accessible communications are provided before, during, and after disasters, it will enable all people to access the health safety and independence support they need to optimize the limited first responder and medical capacity.

Aligning National Health Security Strategy (NHSS) and the goals of these committees:

The Committees are examining national health security issues and priority areas to inform the next NHSS. Areas discussed thus far include improving the distribution of materials (e.g., masks, accessible diagnostic tests, and other medical countermeasures needs) to ensure that accessible instructions exist. They are also promoting the use of national assistive technology, durable medical equipment, and consumable medical supplies to source just in time materials. Thus, ensuring independence during disasters for people who are not in acute or long-term care facilities.

Concluding remarks and adjournment

The next meetings for the NACSD and NACIDD will be scheduled in Spring 2023. Attendees were thanked for their participation and for the information that was shared with committee members. A meeting summary will be posted following the meeting on the ASPR website.

For questions, comments, and concerns, please contact the committees at NACIDD@HHS.gov and NACSD@hhs.gov.

Appendix 1 Public Comments

Public Comments: Live questions from the public through the chat and the phone

Mr. Ramey Wood raised concerns regarding placemaking and if those efforts might be considered a responsive technology or a prescriptive technology. He also raised the idea of anticipatory intelligence as a more affordable investment. He stated he understood that placemaking work seeks to help build the technological and community relationships to respect the very best practice and the needs of a community in disasters, such as telehealth response and technology. Mr. Wood also asked what can be done to aid older persons who live with disabled children to better prepare them for forest fires or earthquakes. Additionally, he shared the Rural Placemaking Initiative. Med Robertson responded by sharing the following resources: TCRP Project A-33 "Communications with Vulnerable Populations: A Transportation & Emergency Management Toolkit" and Transportation Research Board publications.

Nichole Crawford, a Social Worker and Public Health professional working on emergency preparedness for caregivers of persons with dementia, asked how can individuals looking to move emergency preparedness forward assist with the agenda of NACSD and NACIDD? Committee members responded by stating that public comments are one of the best ways to communicate with the Committees and to let them know if they are getting it right or are missing things. These comments make the work more efficient.

Maggie Federico Tougas asked how this proposal differs from anything else that's been done in the U.S. especially at the state and local levels. Will there be funding available to hire staff to push these initiatives forward? She stated she has firsthand experience with the frustration of making sure our disabilities and access functional needs community is prepared and included in mitigation, response, and recovery in the event of an emergency/disaster.

Matthew Purington asked if the Committees will go more into depth about mental health efforts and if they have considered creating a Disabled Mental Health Practitioner working group to advise efforts? Considering that people with disabilities often feel greater anxiety around going to a shelter, because of fears that they'll end up in an institution, sometimes they choose to shelter in place. How can we assure people that they have a right to equal access to shelter in the community, with their family, where they can give and receive family support? What can be done do to increase the numbers of Disabled Healthcare Practitioners and academics as the best option to reduce implicit ableism evidenced by the inability of many medical professionals to accurately gauge quality of life for people with disabilities? Board members stated the role of the Committees is to make recommendations to the Secretary of HHS and the ASPR. These sorts of recommendations may be among the early identified priorities and will be considered in the future.

Sandra L. Aldana, PhD, MPH, a public health professional and longtime Red Cross Disaster Response volunteer, attended a meeting and heard that approximately 20% of people with developmental disabilities, and probably higher rates among people with acquired disabilities, identify as LGBTQ+. Is there some universal design being used to allow for gender neutral sheltering, specific supports, and



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e safe spaces available for them? A

ways to effectively communicate to these groups that there are safe spaces available for them? A committee member stated that this is currently being discussed at the American Red Cross but cannot share details at this time.

An attendee asked if there was a plan for the disabled homeless population to which Ms. Elizabeth Davis shared that Homeless with Disabilities and Emergency Preparedness is a program that addresses this issue 1. Furthermore, Dr. Cheryl Levine of ASPR stated that there is comprehensive Toolkit for Addressing the Needs of Individuals Experiencing Homelessness jointly developed by VA, HHS, and Department of Housing and Urban Development.

George Hawthorne mentioned the importance of food during disasters and how many Home Delivered Meal Programs across the country can be mobile. He stated that it would be important to include this in disaster preparedness.

Andrea Lara stated the importance of telehealth and how the government should develop a plan that is inclusive of the most vulnerable for future disasters. Most vulnerable communities were and still are affected by COVID-19 over two years later and suffering healthcare inequities.

Public Comments, remarks from scheduled public commenters

Dr. Colleen Ryan, Harvard University, raised a question relating to crisis standards of care. How can crisis standards of care be changed to ensure equitable treatment for people with disabilities? Bias against people with disabilities often leads to perceptions of decreased quality of life leading to inadequate or lower level of medical care. People with disabilities should have the opportunity to participate in the production of these crisis standards of care. Cheryl Levine, ASPR, stated that HHS OCR continues to work to address this issue and shared relevant information <a href="https://example.com/here-exam

Kira Meskin Schiff, Community Reintegration Advocate, Progress Center for Independent Living, Vice Chairperson and Illinois Emergency Management Agency Access and Functional Needs Advisory Committee, remarked on the importance of personal protective equipment (PPE) for people with disabilities and caregivers of people with disabilities. Her organization formed during poor PPE distribution and engaged in grass-roots efforts to distribute PPE to the disabled in Illinois going as far as drafting legislation that passed and mandates an advisory committee of the disabled. Personal assistants are considered frontline medical workers, but they're not getting adequate access to PPE. Home and community-based services keep people out of congregate care settings, and more than half of personal assistants are people of color. For much of this pandemic there has been inadequate distribution of PPE

¹ California's "Housing and Disability Advocacy Program" specifically in the cities of Los Angeles and San Francisco offers assistance and services.



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to these people. Also, communications to this group have been inadequate, and access to electronic communications among the disabled can be a problem. All mechanisms of communication—phone, mail, in-person—must be used in addition to digital communications.

Derek Lee, ACL, responded stating that these are very important points about personal care assistants. Area Agencies on Aging can be reached through the dial line 888-677-1199. Additionally, Dr. Cheryl Levine, ASPR, noted that ACL has a funding opportunity focusing on strengthening the direct care workforce called Strengthening the Direct Care Workforce: A Technical Assistance and Capacity Building Initiative. June Kailes specified that the committees are trying to address service deserts with real funding and effective training.

Laura Vitkus, Director of Partner Engagement, AZ End of Life Care Partnership, commented about the importance of making advanced care plans and the importance of organizations such as AZ End of Life Care and their vision to ensure that people receive the care that they want at the end of life.

Samantha Tucker asked the committees for assistance regarding her mother who lives in Kentucky who is 74 a suffered a stroke and is now blind. Ms. Tucker lives in Virginia and asked for guidance on where to seek assistance such as audio applications for her phone or laptop. Committee members will share ideas and information

Appendix 2- Addendum for March 30, 2022, Meeting Summary

The Joint Inaugural Public Meeting for the NACSD and NACIDD on March 30[,] 2022, Meeting Summary did not accurately represent a public comment made during the meeting. The statement has been revised below.

Updated Summary for Ms. Katy Franklin, Hard of Hearing Services, North Carolina Division of Services

Ms. Franklin stated that people who are Deaf, Hard of Hearing, and DeafBlind have a right to the same services as those without hearing loss, and especially during and after a disaster. Despite improvements in telehealth, challenges remain for those with hearing loss having full and effective access to these services. With an increasing population facing hearing loss over the next decade, the lack of access to emergency communications at the local, state, and federal level leaves people isolated and unable to get important and often critical safety information.

People with hearing loss get their information and news about disasters in a variety of ways including through press conferences, online news sources, and social media. Live video on these platforms often has no captioning or poor captioning. Additionally, even though North Carolina Governor's Press Conferences always have American Sign Language (ASL) interpreters embedded, most local press conferences do not. These barriers can create safety problems for people with hearing loss.

Appendix 3- Related Abbreviations

ACL: Administration for Community Living

ASPR: Administration for Strategic Preparedness and Response BARDA: Biomedical Advanced Research Development Agency

CDC: Centers for Disease Control and Prevention

DFO: Designated Federal Official

DHS: Department of Homeland Security ESF 6& 8: Emergency Support Function 6 & 8

FDA: Food and Drug Administration

HHS: Department of Health and Human Services

HUD: Department of Housing and Urban Development

NAC: National Advisory Committee Team

NACIDD: National Advisory Committee on Individuals with Disabilities and Disasters

NACSD: National Advisory Committee on Seniors and Disasters

NHSS: National Health Security Strategy

NIH: National Institutes for Health

SAMHSA: Substance Abuse Mental Health Services Administration

VA: Department of Veterans Affairs