



NATIONAL ADVISORY COMMITTEE ON INDIVIDUALS WITH DISABILITIES AND DISASTERS (NACIDD) PUBLIC MEETING Summary

April 1, 2022

Washington, DC (virtual)

11:30 am -2:00 pm ET

Roll Call

Voting Members

Mrs. Vicky Davidson
Mrs. Julie Foster Hagan
Ms. June Isaacson Kailes
Mrs. Barbara Kornblau
Ms. Donna Platt
Ms. Marcie Roth

Ms. Amy Nicholas, National Council on
Disability

Working Group Members

Dr. Karoly Mirnics
Dr. Rosanne Rushing

Ex Officio

Dr. Cheryl Levine, HHS/ASPR
Ms. Jill Jacobs, HHS/ACL
Ms. Elizabeth Sadove, HHS/FDA
Ms. Lucille Beck, VA
Dr. Sachin Dev Pavithran, U.S. Access Board

Facilitating Designated Federal Official

Ms. Tabinda Burney

HHS/ASPR/NAC Staff

Dr. Maxine Kellman
CAPT Christopher Perdue
LCDR Clifton Smith
Ms. Mariam Haris

Summary

On April 1, 2022 the National Advisory Committee on Individuals with Disabilities and Disasters hosted a public meeting to present the newly appointed voting members with an opportunity to discuss their backgrounds, interests, and expertise. As well as providing the members with presentations on topics of import. Over 100 people attended this meeting virtually.

The mission of the committee is to evaluate and provide input with respect to the medical and public health needs of persons with disabilities related to preparation for, response to, and recovery from all-hazards. The NACIDD is required by Section 2811C of the PHS Act, amended by Section 305 of the Pandemic and All Hazards Preparedness and Innovation Act of 2019 (PAHPAIA, Public Law 112-16) and governed by the provisions of the Federal Advisory Committee Act (FACA) (5 U.S.C. App.).

Introduction

Tabinda Burney, MS, Designated Federal Official, Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response (ASPR)

Ms. Burney introduced the National Advisory Committee on Individuals with Disabilities and Disasters and the mission of the committee to evaluate and provide input with respect to the medical and public health needs of persons with disabilities related to preparation for, response to, and recovery from all-hazards emergencies, and provide advice and consultation on emergency preparedness and response activities relating to persons with disabilities. The NACIDD is required by Section 2811C of the PHS Act, amended by Section 305 of the Pandemic and All Hazards Preparedness and Innovation Act of 2019 (PAHPAIA, Public Law 112-16) and governed by the provisions of the Federal Advisory Committee Act (FACA) (5 U.S.C. App.) and governed by the provisions of the Federal Advisory Committee Act (FACA) (5 U.S.C. App.).

NACIDD Member Introduction

The committee voting and non-voting members introduced themselves during the meeting to provide stakeholders and the public with insight into their professional backgrounds and areas of interest. The NACIDD voting members professional background and areas of interest are available online and biographies are included in Appendix 1.

Presentations

Lessons Learned on the Efficacy of Federal Program and Policies for People with Disabilities Before, During, and After Disasters

Amy Nicholas, Senior Attorney Advisor, National Council on Disability

The National Council on Disability (NCD) is an independent Federal agency responsible for advising the President, Congress and federal agencies on matters affecting the lives of people with disabilities. The NCD focuses on a broad spectrum of issues, including health care, employment, public accommodations, government services, transportation, education, emergency planning and response and long-term services and supports. The NCD drafted the first version of the Americans with Disabilities Act (ADA) that was introduced to the House of Representatives and the Senate in 1988. The NCD also evaluates new and emerging disability policy issues at all levels of Government and the private sector and evaluates and advises through the lens of the ADA and Section 504 of the Rehabilitation Act to assess extent to which policies and programs either facilitate or impede the federal laws.

Ms. Nicholas made reference to three NCD reports related to the ongoing COVID-19 pandemic¹. From this body of work the NCD compiled a list of lessons learned on the efficacy of federal program and policies for people with disabilities before, during, and after disasters. The lessons fall into the following categories: health care, congregate care, effective communications, and emergency management.

Overall, the reports found that the challenges faced with COVID-19 were more pronounced for people with disabilities. COVID-19 led to full health care delivery changes and worsened existing barriers to care. People with disabilities faced multiple layers of health care discrimination during the pandemic. Data collection on infection, hospitalization and death rates for people with disabilities was lacking. What the NCD found was people with intellectual disabilities and medically fragile individuals faced a high risk of being triaged out of COVID treatment when hospital beds and supplies and personnel were scarce. Persons with disabilities were denied the use of personal ventilator devices after admission to a hospital and at times denied assistance of critical support persons during hospital stays. Many crisis standards of care policies established or used by states and hospitals to govern health care services during periods when medical beds, equipment and personnel were strained, discriminated explicitly and implicitly against people with disabilities. The roll-out of the COVID-19 vaccines left out people with disabilities who were at high risk for COVID-19, such as those I group homes with intellectual and developmental disabilities. Vaccine sign-up and delivery was also inaccessible to many people with disabilities across the nation.

Regarding congregate care, COVID-19 exposed many of the worst voluntary of congregate care systems and the weakness of efforts to move these individuals out of these settings and face in the century's first public health crisis, states had less capacity to fund and implement the legally required diversion and transition initiatives. When reports of rapid infection and high death rates exploded across the country, like nursing homes, the primary discussion was related to susceptibility to the virus as to the age of the parents in nursing homes, rarely acknowledging the more than 14% of residents in these facilities are people with disabilities and are younger than 65 years of age. Approximately 600,000 people with disabilities who were living in congregate care facilities on a waitlist for community living transition when the pandemic hit and facility lock downs forced them to remain in those settings throughout the pandemic.

With the pandemic disparities and effective communication deepened. COVID-19 has uniquely impacted Deaf and hard of hearing communities, people who are blind and people who cannot rely on speech to be heard and understood. Today there are over 37.5 million people who are Deaf or hard of hearing and an additional 5 million who cannot rely on speech to communicate. For those people

¹ See Appendix 2 for list.

masking made communication difficult to interact with their communities or access health care. Telemedicine platforms and patient education materials are often not accessible to people with vision loss.

Challenges Faced by People with Disabilities During the COVID-19 Response

Sachin Dev Pavithran, Ph.D., Executive Director, U.S. Access Board

The U.S. Access Board is a small independent federal agency. The Access Board is an independent federal agency devoted to accessibility for people with disabilities. The Access Board develops and maintains design criteria for the built environment, transit vehicles, telecommunications equipment, and for electronic and information technology. With a staff of about 30 and governing board of about 25 members. Many of whom are people with disabilities from different parts of the country with expertise in accessibility. Twelve members of the Board are senior level political appointees from twelve different departments and agencies.

During the pandemic, the Access Board made note of the lack of information distribution to people with disabilities. Much of the information released by federal and state governments was not accessible for the blind or visually impaired, or for the deaf and hard of hearing. Testing sites and vaccination sites were inaccessible to many people with disabilities across the nation. Accessible information was also scarce.

Public Comments

Mr. Bowman, from the North Carolina Department of Public Health and Human Services, asked about the existence of a federal coordinator in North Carolina for the American Red Cross and FEMA that can assist with planning to better serve persons with disabilities for the tropical season. Ms. Marcie Roth provided Mr. Bowman with the details of a full-time access and functional needs coordinator.

Wrap-up

Ms. Burney thanked attendees, committee members, invited speakers, and public attendees for attending the meeting and offered attendees to send comments and questions to the NACIDD at NACIDD@hhs.gov.

Appendix 1: NACIDD Members

NACIDD Voting Members

VICKY DAVIDSON



Vicky Davidson is the Executive Director of the Missouri Developmental Disabilities Council with over thirty-five years of experience working toward statewide systems change and policy development that impacts individuals with developmental disabilities, their families, serving as a strong advocate for people with disabilities. Following Hurricane Katrina, Vicky became active in the emergency management arena with a focus working with individuals with disabilities, their families and providers of services. She managed Missouri's state Health Department's Emergency Response Center for several years and gained experience responding to the H1N1 pandemic, ice storms with massive power outages, flooding, tornadoes and other public health emergencies. Vicky's passion is providing people with disabilities the tools they need for preparedness and recovery from disasters. She serves as Chair of Missouri's Access and Functional Needs Committee. Vicky is a parent and family member of individuals with disabilities who enjoys spending time with her daughter, hiking, biking and nature photography.

ELIZABETH A. DAVIS



Elizabeth Davis is an emergency management consultant focusing on inclusive emergency management, marginalized population planning, disaster human services, and related issues through her firms *EAD & Associates, LLC*, and the *National Emergency Management Resource Center* (NEMRC). Both companies employ a holistic, client-focused approach to providing quality services and real-world solutions.

An accomplished public speaker, Ms. Davis is considered one of the nation's "go-to" sources. She began public service with the NYC Mayor's Office for People with Disabilities as Assistant to Counsel and Senior Policy Advisor. Due to her role as Incident Commander in the Deaf Mexican Nationals slave-ring case in Queens, she was transferred to the NYC Office of Emergency Management as Special Needs Advisor; the first such full

time position in the country. There she was responsible for ensuring that all elements of planning, response, and recovery incorporated the unique needs of the disability community, senior population, and medically dependent persons. She later became the first Director of the National Organization on Disability's Emergency Preparedness Initiative (EPI).

Ms. Davis is also an advisor to DHS and FEMA, sits on many research review boards and serves on several national advisory boards, including as the chair of the National Hurricane Conference Health Care/Accessibility Committee; first chair of the International Association of Emergency Managers Accessibility Committee; and as a founding board member of a not-for-profit the Emergency Preparedness Initiative Global. She has been retained in several legal cases involving inclusive emergency management practices in Maryland, California, and New York. Over the years, she has received many awards and honors for her work. Ms. Davis is an inaugural inductee into the International Women in Homeland Security & Emergency Management Hall of Fame.

Ms. Davis received her JD from Boston University School of Law and her EdM from Boston University School of Education with a degree in the Socio-Bicultural Study of Deafness and American Sign Language. She holds an undergraduate degree with a major in Sociology and a minor in Political Science from Barnard College at Columbia University.

JULIE FOSTER HAGAN



Julie Foster Hagan has served as the Assistant Secretary for the Office for Citizens with Developmental Disabilities in the Louisiana Department of Health since July of 2018. Julie has worked for OCDD for more than 22 years in several leadership roles, including Deputy Assistant Secretary, Administrator of North Lake Supports and Services Center and Program Manager of the statewide OCDD Resource Centers. Her drive is to foster quality improvements in the intellectual / developmental disabilities service delivery system that will help people to have more independent and meaningful lives in the community.

Julie obtained a Bachelor of Arts and a Master of Education degree in the field of Speech/Language Pathology and a Master of Business Administration, with a concentration in Health Care Administration from Southeastern Louisiana University. She is married to Darren and she has one son, four stepchildren, and three grandchildren.

JUNE ISAACSON KAILES



June Kailes is a Disability Policy Consulting with over four decades of experience as a writer, trainer, researcher, policy analyst, subject matter expert, mentor, and advocate (www.jik.com). June focuses on building critical disability practice competencies and capabilities in health care and emergency management by using actionable details. These details operationalize the equity and specificity needed to include people with disabilities and others with access and functional needs. June's work converts the laws, the case laws, regulations, and guidance into tangible building blocks, tools, and operating procedures that close service gaps, prevent civil rights violations and deliver inclusive, equally effective services. June uses the "how, who, what, where, when, and why, for physical, programmatic, communication, and equipment access to get it right! June enjoys biking, traveling, theater, photography, music,

podcasts, reading, and art projects. June doesn't enjoy exercising but does it anyway.

BARBARA L. KORNBLAU



Barbara L. Kornblau is an attorney, an occupational therapist, a certified case manager, a certified disability management specialist, and a person with a disability. She is a professor, (working remotely) and Program Director of Idaho State University's Occupational Therapy Program and a national disability rights advocate. She is a consultant to the United Spinal Association's Pathways to Employment Program. A former Robert Wood Johnson Health Policy Fellow, she worked in the U.S. Senate on health and disability issues for Senators Harkin and Rockefeller. She put together the coalition that got the word "disability" in the Affordable Care Act everywhere "racial and ethnic" appears and has played a key role in advocacy for disability data collection. She is a Past President of the American Occupational Therapy Association and as an occupational therapist, she has consulted with employers, developers, local governments, and others on making things accessible under the Americans with Disabilities Act (ADA). As an attorney, she litigated cases under the ADA, involving discrimination in employment, state and local government services, and health care services. Dr. Kornblau has presented nationally and internationally and is widely published.

DONNA PLATT



Donna Platt is the Emergency Preparedness Coordinator with the North Carolina Division of Services for the Deaf and Hard of Hearing. NCSDSHH works to ensure that all Deaf, Hard of Hearing, or DeafBlind North Carolinians have the ability to communicate their needs and to receive information easily and effectively in all aspects of their lives, especially their health and well-being. Donna has more than 20 years of experience providing consultation, training, resources, and collaboration with emergency responders and 9-1-1 telecommunicators in North Carolina and in Washington State. Her area of focus is effective communication in 9-1-1 technologies and throughout all phases of emergency management. Donna has both professional and personal experiences with emergency events since 2016 including Hurricanes Matthew and

Florence and a FEMA COVID-19 vaccination site. She is currently involved in numerous work groups in the NC Emergency Management's Human Services Branch and serves as the National Emergency Number Association's Accessibility Committee Co-Chair. In addition, she is a prior member of several national committees including the Integrated Public Alert and Warning System (IPAWS) Subcommittee under Federal Emergency Management Administration's National Advisory Council.

Donna has a Master of Science in Education Technology from Gallaudet University and a Bachelor of Science in Social work from the Rochester Institute of Technology. Donna enjoys reading, hiking, and traveling.

MARCIE ROTH



Marcie Roth is Executive Director and CEO of the [World Institute on Disability](#), one of the first global disability-led organizations, advancing the rights of 1.3 billion people with disabilities worldwide. She was recently named by Forbes Magazine to their inaugural [Fifty Over 50 Impact List](#), and by Womens eNews as one of their [21 Leaders for the 21st Century](#). Marcie he has served in executive leadership roles for advocacy and public policy organizations since 1995, leading coalitions committed to operationalizing accessibility and inclusion as intersectional imperatives for equity, diversity and

global social justice.

In the immediate aftermath of the 9/11 terrorist attacks, Marcie turned her advocacy towards improving emergency preparedness and disaster outcomes for people with disabilities, building accessible disaster-resilient communities and disability inclusive climate justice initiatives.

Appointed by President Obama to the U.S Department of Homeland Security - Federal Emergency Management Agency (FEMA) from 2009 to 2017, she served as Senior Advisor to the FEMA Administrator, establishing and directing the Office of Disability Integration and Coordination. Marcie represented the U.S. government internationally as an expert on whole community inclusive global disaster risk reduction from 2012- 2017 and has served as a leader throughout the development and implementation of the United Nations *Sendai Framework for Disaster Risk Reduction 2015-2030*.

Marcie provides expert consultation to governments, corporations, health systems, and the United Nations. She launched the [Global Alliance for Disaster Resource Acceleration](#) (GADRA) in 2020, bringing corporate and foundation funders together with local disability-led organizations to accelerate humanitarian relief directly to disaster-impacted communities where and when it's needed most. Under her leadership, GADRA is currently assisting Ukrainian disability-led organizations in an urgent effort to be sure at least 2.7 million Ukrainian children and adults with disabilities are not left behind.

Recently appointed as a public member of the United States Delegation to the 66th Session of the United Nations Commission on the Status of Women, Marcie is a Harvard University Kennedy School of Government Senior Executive Fellow with a BS in Public Safety Administration.

NACIDD Working Group Members

Károly Mirnics, MD, PhD, ACHE

Director, Munroe-Meyer Institute for Genetics and Rehabilitation
Hattie B. Munroe Professor of Psychiatry, Pharmacology and
Experimental Neuroscience, Biochemistry & Molecular Biology, UNMC
Omaha, NE

Rosanne Rushing, DrPH

Inclusive Health Policy Lead
Humanity & Inclusion
Washington, DC

Christine Woodell, MS

Founder and CEO
ADA Services, Inc.
Ocean Springs, MS

Appendix 2

National Council on Disabilities Referenced Reports

- [NCD's 2021 Progress Report: the Impact of COVID-19 on People with Disabilities.](https://www.ncd.gov/progressreport/2021/2021-progress-report)
<https://www.ncd.gov/progressreport/2021/2021-progress-report>
- [Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters.](https://ncd.gov/publications/2019/preserving-our-freedom)
<https://ncd.gov/publications/2019/preserving-our-freedom>
- [Effective Communications for People with Disabilities: Before, During, and After Emergencies.](https://ncd.gov/publications/2014/05272014)
<https://ncd.gov/publications/2014/05272014>