U.S. Department of Health & Human Services

Office of the Assistant Secretary for Preparedness & Response

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

# Public Meeting Summary

## April 20, 2023

ASPR

aspr.hhs.gov

# National Advisory Committee on Individuals with Disabilities and Disasters

# Public Meeting Summary

April 20, 2023 (Virtual with ASL/CART services provided)

11:00AM – 1:30PM ET

## Attendees

### Voting Members

- Ms. Vicky Davidson
- Ms. Elizabeth Davis
- Ms. Julie Foster Hagan
- Ms. June Kailes
- Ms. Barbara Kornblau
- Ms. Donna Platt
- Ms. Marcie Roth (Chair)

### Ex Officio Members and Alternates

- Dr. Daniel Dodgen, Administration for Strategic Preparedness and Response (ASPR)
- Mr. John Daly, Federal Emergency Management Agency (FEMA)
- Dr. Karyl Rattay, Centers for Disease Control and Prevention (CDC)
- Dr. Amy Nicholas, National Council on Disability (NCD)

### Subject Matter Experts

- Dr. Roseanne Rushing

### Invited Speaker

- Dr. Julia Limage, Director, Office of Strategy, Policy, and Requirements, ASPR

### ASPR Staff

- Ms. Tabinda Burney
- Dr. Maxine Kellman
- LCDR Cliffon Smith
- Dr. Lara Lamprecht
- Mr. Darrin Donato
- Ms. Mariam Haris
- Ms. Megan Hoffmann
- Ms. Laura Gardiner

## Overview

The National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD or "the Committee") held a Public Meeting on April 20, 2023 to discuss recommendations that the Committee is drafting for the Department of Health and Human Services (HHS) and the Administration for Strategic Preparedness and Response (ASPR) regarding challenges, opportunities, and priorities for national public health and medical preparedness, response, and recovery, specific to the needs of people with disabilities in disasters. Recommendations were discussed, but not finalized and public comments were heard.

## Opening Remarks

### Designated Federal Official, Ms. Tabinda Burney

Ms. Tabinda Burney opened the NACIDD Committee meeting, conducted roll call, and reviewed administrative and operations requirements specific to the NACIDD Charter, the Federal Advisory Committee Act (FACA), the General Services Administration (GSA) FACA Final Rule, and HHS ethics rules for special government employees (the Committee's voting members) appointed by the HHS Secretary.

### Director, Office of Strategy, Policy, and Requirements, ASPR, Dr. Julia Limage

Dr. Julia Limage welcomed and thanked Committee members, HHS colleagues, interagency partners, and the public. Dr. Limage highlighted how HHS's mission relies heavily on collaboration with partners in the private sector, government, and in civil society to prepare for, respond to, and recover from disasters. Substantial collaboration is needed to respond to disasters such as extreme weather events, compounding health events, and known and unknown emerging threats, specifically for medical countermeasures. The Administration for Strategic Preparedness and Response has released the ASPR Strategic Plan, the Quadrennial National Health Security Strategy, as well as its Implementation Plan and Evaluation of Progress to Congress. There is collaboration across ASPR in the areas of climate change and health equity to support healthcare systems and communities.

Dr. Limage also talked about the recent reorganization within ASPR as an important step in the evolution of ASPR as an administration and operational division within HHS. She also discussed the efforts being made within ASPR to incorporate diversity, equity, inclusion, and accessibility considerations in its programs and activities. To conclude her remarks, Dr. Limage emphasized the importance of working in collaboration and in conjunction with the advisory committees to use the recommendations provided to help shape ASPR and HHS priorities.

### Chairperson, NACIDD, Ms. Marcie Roth

Ms. Marcie Roth, Chairperson of the NACIDD, welcomed attendees and thanked the Committee members for their hard work in drafting recommendations. She mentioned how the NACIDD has been in existence for about one year and was chartered to provide expert advice and consultation to ASPR and HHS. Ms. Roth talked about the advisory role of the committee to inform federal government actions and decisions; the committee doesn't have administration and oversight or accountability roles. Ms. Roth also acknowledged the diversity of backgrounds including the non-federal subject matter experts and federal agency ex officio members who enrich the discussion and perspectives on the committee as each issue is considered.

Ms. Roth reported that there have been 57 concurrent major disaster declarations this year; many of the disasters have catastrophically impacted communities. She also discussed that COVID-related hospitalizations and deaths are still very much a daily reality of the healthcare system. Ms. Roth emphasized how many of the people who died during the last three years of the COVID-19 Pandemic were described as elderly, with comorbidities, immunocompromised and frail, these terms are also used often to describe people with disabilities who are entitled to civil rights protections and equity. Despite the civil rights protections offered, there is a disproportionate number of people with disabilities,

marginalized people of color, and others with intersecting identities, all who make up 26% of the U.S. population, many who have lost their lives to COVID-19 while in institutions, nursing homes, psychiatric hospitals, carceral facilities, group homes, and other congregant settings, as well as at home within their communities. Ms. Roth underscored that when people with disabilities are included in communities, they can help improve disaster outcomes for the whole of community.

Ms. Roth said that the NACIDD compiled a list of issues which were refined and prioritized under working groups. The working groups invited federal representatives to speak about their programs and activities to help the committee develop some recommendations for improvement. The draft report that is posted online represents the first five recommendations that were developed by the committee. Ms. Roth also acknowledged the contribution of many of the guest speakers who provided research and presentations to help with the development of the recommendations including the HHS Centers for Medicare and Medicaid Services (CMS), Office for Civil Rights (OCR), as well as several programs and offices within ASPR, among others.

## Draft Recommendations

The Committee reviewed, clarified, and justified each of the five proposed recommendation for the public.

*Recommendation #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.

*Recommendation #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.

*Recommendation #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.

*Recommendation #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.

*Recommendation #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.

The full draft of the recommendations can be found on the ASPR website. Some edits were made to the recommendations through discussion during the deliberation phase of the meeting. The edits included adding details that would broaden the scope of the recommendations and avoid gaps and make improvements to the rationale or justification. The Committee will take additional input from the public and review the recommendations again before voting on them during a subsequent public meeting.

## Public Comments

The public was offered an opportunity to partake in the deliberative process of the NACIDD. Members of the public sent comments to the Committee and were also selected to voice their comments during the meeting. Written public comments were shared with and discussed by the Committee.

Michelle Cohen, mother and advocate for her daughter who is a person with a disability, spoke to the Committee on the Home and Community-Based Services 1915(c) waivers that States can offer under Medicaid. Ms. Cohen highlighted 1915(c) waivers and requirements for families which includes rules for families to follow but does not offer training or protection for families/caregivers. In some instances, families are not given remediation or corrective actions for people living in their homes 24/7 and family members/caregivers are incarcerated. Ms. Cohen requested input for families in such situations. The Committee responded by stating that this shows the importance of communications and getting communications materials to those who need it.

Karen Phoenix, Project CARE Family Consultant, requested suggestions from the Committee for people with dementia who have caregivers and people with dementia who do not have caregivers in the planning process. The Committee members stated that they are considering the needs of individuals and the supports and services that are provided to them and hope to make recommendations that will further aid in planning and providing support during a public health emergency or disaster.

Dr. Jeffrey Silberzweig, American Society of Nephrology (ASN), provided comments on the COVID-19 pandemic relating to individuals with kidney diseases. He provided details on the millions of Americans living with kidney diseases who were adversely affected by COVID-19, and the most vulnerable being individuals in the Medicare population with kidney failure. The disproportionate share of those with comorbidities and compromised immune systems come from historically marginalized communities. Dr. Silberzweig highlighted how the end of the public health emergency (PHE) declaration threatens to widen these disparities unless urgent action is taken to mitigate these anticipated untoward consequences that threaten to exacerbate underlying inequities. The Committee recognized that people with disabilities and those who are immunocompromised are often the most vulnerable to infectious diseases and talked about how they are working to address these post-PHE concerns.

## Final Remarks

The Chair, Ms. Roth, and the DFO, Ms. Burney thanked all the participants and public for joining the NACIDD public meeting. The NACIDD will meet again to deliberate and vote on the recommendations; and welcomes questions, comments, and feedback. The NACIDD can be contacted at NACIDD@hhs.gov.

# Appendix 1: Public Comments

**Full Comments Submitted by American Society of Nephrology (ASN), Dr. Jeffrey Silberzweig**

Comments on the COVID-19 Pandemic Relating to Individuals with Kidney Diseases

April 13, 2023

On behalf of the more than 37,000,000 Americans living with kidney diseases and the 21,000 nephrologists, scientists, and other kidney health care professionals who comprise the American Society of Nephrology (ASN), thank you for the opportunity to provide these comments to the Administration for Strategic Preparedness and Response (ASPR), National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD).

The impact of the COVID-19 pandemic on Americans with kidney diseases has been dramatic. Individuals with kidney failure were the most vulnerable cohort to COVID-19 in the Medicare population. For the first time in the 50-year history of the Medicare End-Stage Renal Disease (ESRD) program, the population of patients treated by maintenance dialysis decreased in 2020. Sadly, the difference is attributable to the disproportionate impact of pandemic-related mortality in this vulnerable population rather than advances in preventing kidney failure. Early in the pandemic, the U.K. reported evidence of viral spread in outpatient dialysis facilities. Individuals receiving dialysis, if infected, had a worse prognosis than the general infected population. Data shared by dialysis providers documented that many individuals with kidney failure lose antibody protection more quickly than the general population. People who are immunosuppressed due to a transplant are particularly vulnerable to COVID and its complications as these individuals often do not mount or maintain the same protective immune response to vaccination as does the general population. In general, kidney transplant recipients with COVID-19 affected by underlying comorbidity and chronic immunosuppression demonstrated higher morbidity and mortality than non-transplant patients with COVID-19. In all of these observations, kidney care teams needed to learn “on the fly,” use best available knowledge to solve problems, and then share the knowledge to improve the trajectory of this deadly pandemic.

Beyond their compromised immune systems, a disproportionate share of these individuals are from historically marginalized communities. The pandemic has caused loss of employment or housing, disruption of educational systems, and increased rates of food insecurity. These challenges are felt disproportionately in historically marginalized communities with limited social and economic reserves. The end of the PHE threatens to widen these disparities unless urgent action is taken to mitigate these anticipated untoward consequences that threaten to exacerbate underlying inequities. In the face of the devastating COVID-19 pandemic, the kidney community collaborated to provide opportunities which promised to serve kidney patients and professionals long into the future. In March 2020, the American Society of Nephrology (ASN) formed the COVID-19 Response Team as a forum to gather accurate, unbiased information from reliable sources, and to share it broadly with the kidney community, regionally, and nationally. The pandemic’s ever-changing realities required continuous refinement and underscored

the need to learn from one another's experience. ASN's COVID-19 In-patient and Acute Kidney Injury (AKI) subcommittee learned much from early experience in urban hospitals stressed with COVID-19 care. They described the need for a nephrologist to be a primary member of the hospital disaster planning committee, and in particular, inform the need for advance planning for staff, equipment, dialysis solutions, filters, medications, and personal protective equipment (PPE). They discussed the need to prepare lactate-and bicarbonate-based dialysate, longer dialysis machine blood lines to accommodate nurse and machine placement outside of ICU rooms, and anticoagulation protocols. When an acute shortage of continuous kidney replacement (CKRT) machines threatened the need for kidney replacement therapy rationing, AKI professionals described the successful use of CKRT machines intermittently for two or more patients. The use of acute peritoneal dialysis to treat AKI during the pandemic was accelerated in several hospitals.

In the outpatient dialysis arena, facilities quickly learned that patient and staff screening, segregation of infected patients and patients under investigation from the general dialysis population, universal face masks, careful staff hand hygiene and gloving between patients, gowning, eye protection and routine surface cleaning all but stopped viral transmission between patients and staff.

ASN's COVID-19 Kidney Transplant team shared experience regarding immunocompromised transplant patients' susceptibility to infection, complications and death. ASN constructed webinars and seminars in conjunction with the American Society of Transplant (AST) to share knowledge and best practice. ASN shared information on safely re-opening transplant procedure in epicenters of COVID-19 infection, immunosuppressive medication protocols for infected patients and those under investigation, and organ procurement safety during a pandemic.

The importance of attending to mental wellness issues among both patients and staff was a major concern during the COVID-19 pandemic. The ASN COVID-19 Outpatient Dialysis Subcommittee developed a learning module and presented webinars dealing with compassion fatigue, a common phenomenon in a stressful, long-lasting pandemic. Not surprisingly, many patients and staff found these resources very helpful.

ASN worked with CDC and the White House to establish a mechanism to deliver COVID-19 vaccines directly to patients and staff in dialysis facilities, increasing substantially the numbers of immunized individuals especially among under-represented communities. The utility of monoclonal antibody treatment early in SARS-CoV-2 infected patients, and later as prophylactic therapy, was shared in webinars and round-table discussions.

By providing a resource for clinical leaders across the country to share concerns, questions, potential solutions, and best practices, the kidney care community collaborated to rapidly disperse knowledge, and promote best practices. The ASN COVID-19 Response Team through its collaborations with CDC and other healthcare agencies, dialysis chief medical officers and partners throughout the kidney care community demonstrated very strong interest in ongoing partnership. Virtually every person who was invited to participate in Response Team activities accepted the challenge and contributed generously. The 21st century challenge is to improve data collection, aggregation, and interpretation tools, so that real-time query of databases can give timely information to test clinical hypotheses and improve care. This

experience should better prepare us should another pandemic or other health care emergency challenge the kidney care community.