



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families

February 14, 2022

Dear Disability Community Stakeholders:

The health and well-being of people with disabilities have long been ignored in this country despite the existence of an overwhelming body of studies and reports that unequivocally document the significant and continuing prevalence of health disparities that exist between persons with disabilities and our nondisabled counterparts.

The latest contribution to that body of work is a [December 2021 study](#) appearing in *JAMA, Risk of Adverse Maternal Outcomes in Pregnant Women with Disabilities*, revealing significant maternal health disparities between women with physical, sensory or intellectual disabilities, compared to women without disabilities. As addressed in the study, women with disabilities had higher risk of gestational diabetes, placenta previa, premature rupture of membranes, preterm premature rupture of membranes, and postpartum fever as well as maternal death. The study cites a number of contributing factors to these disparities, including providers' lack of clinical knowledge of their patients' disabilities, providers' negative attitudinal disability beliefs, and their low-level of comfort in managing pregnancies among women with disabilities. All of those factors are recurring themes contributing to the lack of health equity for people with disabilities.

That considerable body of research underscores that *indifference, inattention, and ignorance* have prolonged those disparities, and as we have witnessed during the pandemic has left people with disabilities vulnerable to contracting the COVID-19 virus and less resilient to combat against its effects. Despite the decades-long existence of federal nondiscrimination mandates, people with disabilities are still subjected to pervasive and systemic discrimination by healthcare providers, which exacerbates those disparities -- and providers do so while supported by federal financial assistance. Enough.

With the release of *Health Equity Framework for People with Disabilities*, the National Council on Disability (NCD) calls for an all-of-government approach to comprehensively address the health needs of the over 64 million people with disabilities in this country and in our territories. The framework requires the combined action of Congress; the Departments of Health and Human Services; Justice; Education; and Veteran Affairs. While the framework contains 39 discrete components, there are four foundational

pillars – special medically underserved population designation; disability clinical-care curricula development and adoption; disability data capturing; and accessible medical diagnostic equipment enforceable standards. Individually and collectively those foundational components are critical to achieving health equity for people with disabilities, and the remaining components flow from their adoption and implementation.

Last February, in my [Vision and Priority Statement](#), I articulated that NCD's abiding focus during my tenure as Chairman will be on the healthcare needs of people with disabilities. The *Health Equity Framework* is a result of that focus. During the last 10 months developing the framework, we met with representatives of national disability rights organizations and sought counsel and input from a multi-disciplinary *Dream Team* of our country's leading experts on disability health equity, health disparities and healthcare accessibility, each of whom have dedicated their professional lives to addressing the healthcare needs of people with disabilities. We also have met and communicated with the Administration's Domestic Policy Council, numerous offices within various federal agencies, and with staff of congressional committees that have jurisdictional responsibility for various components of our framework to begin discussions regarding the framework's components. We have also had discussions with organizations outside of government, such as The Joint Commission, which accredits more than 22,000 U.S. health care organizations and programs, soliciting their support to undertake specific measures addressing certain aspects of the health inequity faced by people with disabilities.

All of those meetings and discussions helped shape the framework. As we met, we learned of certain federal agencies' and departments' ongoing actions to address our framework components. For example, with input from NCD and its *Dream Team*, the Office of the National Coordinator for Health Information Technology has begun efforts to address the uniformly lacking disability-related data in public health surveillance programs. Last September, the Department of Health and Human Services Office of Civil Rights announced its intent to pursue rulemaking under Section 504 of the Rehabilitation Act of 1973. NCD has consistently advised that those proposed rules will require the adoption and implementation of accessible medical diagnostic equipment standards, translating the US Access Board's 2017 voluntary standards into enforceable regulations. Similarly, in December the Department of Justice in the [Unified Regulatory Agenda](#) revealed that it will issue its Advance Notice of Proposed Rulemaking addressing accessible medical diagnostic equipment in September 2022.

In furtherance of NCD's disability policy advisory mandate, we will continue to assist those agencies in their efforts. We will also continue advising the respective congressional committees with jurisdictional authority over the various components of our *Health Equity Framework* for consideration of legislative adoption and implementation. Over the course of this year, we will organize convenings to help better inform our federal partners on the necessity of certain components of our *Health Equity Framework* and implementing our recommended targeted solutions.

While there is still a significant amount of heavy lifting required to advance our *Health Equity Framework*, we express our profound gratitude to our *Dream Team* of advisors: Dr. Lisa Iezzoni, Dr. Kristi Kirschner, Dr. Margaret Turk, Dr. Priya Chandan, Professor Elizabeth Pendo, JD; Dr. Rosaly Correa-de-Araujo, Professor Barbara Kornblau, JD; Dr. Bonnie Swenor, Dr. Susan Havercamp, Dr. Michael McKee, Dr. JoAnne Theiry, Dr. Deborah Klein Walker, Dr. Cheri Blauwet and to NCD council member, Dr. Rick Rader, for their invaluable assistance in critiquing the framework and assistance in its development. We will continue to rely on our *Dream Team* as we move forward. Additionally, my deep appreciation to NCD's health equity subcommittee, Vice Chairman Jim Brett, immediate past Chairman Neil Romano, and Dr. Rick Rader for their many hours of work in developing the framework and NCD's Senior Staff Attorney Advisor Amged Soliman for spearheading the work of the subcommittee.

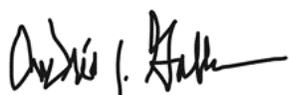
One out of every four people in this country and our territories report having a disability. Disability, whether acquired at birth or over the course of one's lifetime, is a natural part of the human condition. The fact that the significant health disparities between people with disabilities and their nondisabled counterparts have been known but not addressed can no longer be tolerated. The fact that disability-based discrimination continues systemically and pervasively within our healthcare sector with the support of federal funds is alarming and should be a concern to all.

In his special message to the Congress on national health needs, in February 1962, President John F. Kennedy stated ". . . one true measure of a nation is its success in fulfilling the promise of a better life for each of its members. Let this be the measure of our nation." Approaching 32 years ago this July, a federal promise was made to people with disabilities - a promise of independence, freedom of choice, control of their lives and the opportunity to blend fully and equally into the rich mosaic of the American mainstream; or as articulated by President George H.W. Bush, "a federal guarantee of fair and just access to the fruits of American life." We have failed in that promise. Attaining and maintaining good health is the predicate for engaging in every aspect of American life. As long as maternal health disparities exist between women with

physical, sensory or intellectual disabilities compared to women without disabilities; as long as people with physical, intellectual or developmental disabilities have a life expectancy that is less than half of someone without disabilities; as long as people with disabilities are significantly more likely to have unmet medical, dental and prescription needs than those without disabilities; and as long as disability-based discrimination remains pervasive and systemic throughout our healthcare system aided by federal funds, our great nation carries a shameful blot on its measure of success.

We look forward to engaging the Administration, Congress, our federal partners, and the disability community on the details of our *Health Equity Framework* and making the current absence of all of its components historical reference.

In Solidarity,

A handwritten signature in black ink, appearing to read "Andrés J. Gallegos". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Andrés J. Gallegos
Chairman