



# National Council on Disability

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## NCD Equity Action Plan – March 2023

### Executive summary:

**National Council on Disability** – Our mission is to be a trusted advisor to the President, Congress, federal agencies, and other policymakers regarding matters that affect the lives of people with disabilities. We fulfill this advisory role by engaging in thorough research endeavors that offer major findings and recommendations to policymakers; and by convening stakeholders to acquire timely and relevant input regarding the greatest needs within the hugely diverse disability community.

NCD will continue to advise policies, practices, and procedures that advance equity and remove barriers for people with disabilities. We will do this by continuing to brief Congress and the Administration regarding findings and recommendations from our research into the following areas:

- Health equity and equitable healthcare for people with disabilities;
- Environmental injustice and the impact of climate change and extreme weather events on people with disabilities;
- Disparities and provider coverage challenges facing people with intellectual and developmental disabilities (I/DD) for oral healthcare;
- States' use of quality adjusted life year (QALY)-based cost-effectiveness reports or international drug prices that rely upon the QALY to inform coverage decision in their Medicaid programs and whether it has resulted in restricted access to treatments;
- The state of the nation's home and community-based services (HCBS) in place prior to and during the COVID-19 pandemic that contributed to the inability of residents with ID/DD to transition to lesser-density community housing options, proposing a comprehensive plan to increase community living options with necessary services and supports in view of the recent significant funding for HCBS in the Infrastructure Investment and Jobs Act (P.L. 117-58);
- Disparate Treatment of Puerto Rico Residents with Disabilities in Federal Programs and Benefits;
- The long-standing tax policy exclusion for employees with disabilities in congregate work settings ("sheltered workshops") that results in "dueling classifications" that conflict with other federal employment statutes and results in a question whether people with disabilities are "clients" or "employees," which has significant import regarding eligibility for benefits under the Federal Insurance Contribution Act (FICA) and other federal employment benefits;
- The exclusion of people with disabilities in the SBA 8(a) Business Development Program; and

- The need for federal emergency and disaster preparedness that is inclusive of the needs of people with disabilities.

**Summary of accomplishments:**

Since EO 13985 was released, NCD has advanced equity and removed barriers for people with disabilities in the following ways:

- Strongly and repeatedly advised policymakers on how the COVID-19 pandemic is affecting people with disabilities and called for specific provisions within COVID relief packages.
- Researched and advised policymakers on the broadscale impacts of COVID-19 on the lives of people with disabilities.
- Met with Deputy CMS Administrator Seshamani to request guidance to states on the availability of Medicaid waivers to retain Direct Service Providers during the pandemic.
- Advised National Governors Association regarding priority vaccine allocation for people with disabilities based upon the disproportionate impact of COVID on people with disabilities; and made recommendations regarding data collection related to the pandemic.
- Advised new leadership at the U.S. Department of Health and Human Services (HHS) to take regulatory action on discriminatory bias and practice rampant in the nation’s health care system based upon NCD’s body of research.
- Published an article in *Health Affairs* blog titled, “Misperceptions of People with Disabilities Lead to Low-Quality care: How Policy Makers Can Counter the Harm and Injustice,” which raised the profile of health disparities and inequities for people with disabilities.
- Presented on health inequity at the Disability and Philanthropy Webinar Series: “Health Equity and Disability – Presidents’ Council on Disability Inclusion in Philanthropy.”
- Chairman Gallegos spoke at White House’s “The Time is Now: Advancing Equity in Science and Technology” Disability Pride Month Roundtable.
- Chairman Gallegos participated in a White House roundtable with leaders and advocates from disability-focused organizations sharing expertise in science, technology, engineering, and mathematics (STEM), stressing the necessity of ensuring people with disabilities can visualize a pathway to a STEM career by seeing people like them at the highest levels within those organizations; be it laboratories, universities, engineering firms, or federal agencies.
- Released and provided a briefing webinar for over 498 registrants on our *Enforceable Accessible Medical Equipment Standards – A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* report about health disparities and inequities that highlights the double effect of disparities for people of color with disabilities.
- Collaborated with the Administration on Community Living to update NCD’s 2003 Native American Toolkit, titled “Understanding Disabilities in American Indian and Native Alaskan Communities” via a Memorandum of Understanding between NCD and the National Indian Council on Aging.

- Researched and advised on the disparate treatment in federal programs of Puerto Ricans with disabilities residing in Puerto Rico.
- Informed by meetings with representative nonprofits of NCD's constituency, developed and released a comprehensive health equity framework to ensure health equity for persons with disabilities.
- Met with FEMA Administrator Criswell to discuss how people with disabilities are accounted for in preparation and recovery from emergencies, including how to ensure they do not become unnecessarily institutionalized; reinvigorated roundtable discussions with FEMA and stakeholder groups re: ongoing concerns regarding specific FEMA policies.
- Met with the Department of Homeland Security Civil Rights and Civil Liberties (CRCL) to discuss equal distribution and availability of FEMA programs and funding before, during, and after disasters.
- Met with Office of the Assistant Secretary for Emergency Preparedness to ensure HHS's Health Security Strategy is inclusive of people with disabilities in public health emergencies.
- Met with FEMA's Director of the Office of Disability Integration and Coordination (ODIC) to discuss how NCD and ODIC can continue to work together to improve the outcome of people with disabilities before, during and after disasters.
- Attended multiple meetings with the National Advisory Council on Individuals with Disabilities and Disasters (NACIDD) on ways to support and enhance public health and medical preparedness, response activities, and recovery, for people with disabilities.
- Researched and advised on health equity through examination of ways to incentivize oral healthcare providers to treat patients with intellectual and developmental disabilities (I/DD) through Medicaid.
- Researched and advised on health equity through examination of the state of the nation's home- and community-based services prior to and during the pandemic that contributed to the widespread deaths of people with intellectual and developmental disabilities (I/DD) living in congregate settings during the pandemic.
- Held a public event to coincide with the release of the report *Strengthening the HCBS Ecosystem – Responding to Dangers of Congregate Settings during COVID-19*.
- Researched and advised on health equity through examination of methods to put value on healthcare interventions, like prescription medicines and other treatments, that do not rely on the use of cost-effectiveness analysis – a method that utilizes the quality-adjusted life year (QALY), which has been shown to discriminate against persons with chronic illnesses and other disabilities.
- Published a fact sheet outlining established voting rights for people with disabilities on our website's resources page.
- Offered policy advice to RSA in developing guidance to clarify the Vocational Rehabilitation (VR) program's criterion for an "integrated employment location" and improve VR program participants' ability to exercise informed choice.

- Presented on NCD’s technology recommendations at the 2021 Forum in March. NCD also assisted the Wireless RERC in informing our constituents of the RERC’s survey seeking people with disabilities and older adults for their survey on access to COVID-19 information.
- Met with the Joint Commission (on hospital accreditation) concerning disability competency training of medical professionals and other interests of people with disabilities.
- Drafted disability cultural competency curricula framework to be recommended for adoption by the majority of US medical schools that have yet to train medical professionals in the appropriate treatment of people with disabilities.
- Advised the National Institute on Minority Health and Health Disparities (NIMHD), and the Agency for Healthcare Research and Quality (AHRQ) on the significant health disparities and poor health outcomes of millions of people with disabilities and recommended that people with disabilities be designated as a “health disparity population,” as NIMHD is authorized to do under 42 U.S.C. Section 285t(d)(1).
- Held a roundtable of physicians, therapists and consumers on the health benefits provided by wheelchair elevation systems and the need for CMS to cover these devices.
- Met with the Department of Justice’ Office of Justice Programs and the Department of Education’s Office for Civil Rights, regarding the high prevalence of sexual assault of students with disabilities on college campuses and the need for the federal government to include disability as a demographic in all surveys that gather data on campus crime and sexual assault.
- Regularly met with Amtrak to provide input on the accessibility of stations, platforms, trains, and online reservations, for people with disabilities.
- Met with the Department of Education’s Department's Office for Civil Rights to advise on ways to improve the current Section 504 regulations to better meet the needs of students with disabilities.
- Presented on NCD’s Health Equity Frame at the National Committee for Quality Assurance Health Summit.

**Equity action plan:**

**Action 1 – Release a report advising on the impact of climate change and environmental injustice on people with disabilities**

In view of Executive Order 13990, “Protecting Public Health and the Environment and Restoring Science to Tackle the Climate Crisis;” and Executive Order 14030, “Climate-Related Financial Risk” directing federal agencies to take a whole-of-Government approach to increase resilience to the impacts of climate change and protect public health, NCD’s annual, statutorily mandated 2022 progress report will address the impacts of climate change and environmental injustice on the lives of people with disabilities.

Environmental injustice occurs when minority groups and/or people living in poverty are excluded from environmental decision-making or are disproportionately exposed to environmental hazards. People with disabilities represent 15% of the world’s population and as the increased

frequency of extreme weather events and other environmental issues increase, the disability community disproportionately absorbs the impact. According to a 2020 United Nations report, people with disabilities are at increased risk of the adverse impacts of climate change, including threats to their health, food security, water, sanitation and, livelihoods. Sudden onset of natural disasters and slow onset events can seriously affect a person with a disability's access to food and nutrition, safe drinking water, sanitation, healthcare services and medicines, education and training, adequate housing, and employment.

NCD's report presents data and evidence on the specific issues people with disabilities encounter due to the impact of the increased frequency of extreme weather events and economic injustice. Specifically, the impact, on a person with a disability's health, access to food, housing, water and sanitation, education, access to the community, and employment. This report offers recommendations on how to mitigate the impact of the increased frequency of extreme weather events and environmental injustice on persons with disabilities. This report discusses the intersectionality of disability and how the individual's specific intersectionality impacts their ability to mitigate and access resources to mitigate the impact of environmental injustice or the increased frequency of extreme weather events.

Given NCD's micro size, small staff of 12, and small lump-sum appropriation, NCD generally tracks progress made on its recommendations from its research reports to policymakers by regularly meeting with leaders and staff from within the Administration and Congress to determine what has been implemented and enforced. If we don't see action on our recommendations over time, we typically reengage and update our research and recommendations on a 5- to 10-year cycle by topic.

NCD closely tethers to its strategic plan its work on research reports for policymakers. Each of our research projects that include the assistance of outside contractors utilizes schedules of deliverables that keep the agency on track with its projects. The agency reports on its progress on each of our current projects, including this one, at our public quarterly board meetings, and our competitively sourced agreements are publicly posted on our website and grants.gov. When all reports are completed, they are released publicly and posted online on our website.

## **Action 2 – Phase II of I/DD Oral Healthcare Medicaid Project (Incentivizing Providers)**

A significant oral health disparity exists for people with I/DD. Studies have shown that adults with developmental disabilities are at risk for multiple health problems including poor oral health. Further, in 2002, the U.S. Surgeon General reported that, compared with other populations, "adults, adolescents, and children with [intellectual disability (sic)] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care." This disparity has made people with I/DD more likely to have poor oral hygiene, periodontal disease and untreated dental caries than members of the general population. Equally noteworthy is the comprehensible frustration and sense of injustice this disparity creates, a disparity created in part by an insufficient number of oral healthcare providers willing to treat patients with I/DD through Medicaid.

Approximately 60 percent of people in the United States with I/DD rely on Medicaid for their health insurance coverage; and effective coverage is no doubt dependent on a sufficient number of

providers willing to participate in the program and provide preventive treatment to patients with I/DD. There were about two million annual emergency department visits in the United States for nontraumatic dental problems, representing 1.5% of all emergency department visits, as of 2015. People with I/DD tend to have higher rates of emergency department visits when compared with people that do not have I/DD. Increasing the number of providers participating in Medicaid programs that provide preventive oral healthcare services to patients with I/DD decreases the need of this patient population to take the more arduous route of obtaining oral healthcare in emergency departments.

Determining what programs might incentivize providers to treat patients with I/DD through Medicaid is a vital component of achieving best approaches towards realizing the policy proposal of improving access to oral health preventive care for patients with I/DD. For this project a questionnaire will be disseminated to oral healthcare providers to determine why more providers do not participate in Medicaid programs and waivers that allow for the treatment of patients with I/DD. The questionnaire will further query oral healthcare providers about potential incentives that could rectify that problem. Additionally, the report will establish a method by which states could potentially calculate a comprehensive return-on-investment for investments that result in increased provider participation that go beyond healthcare costs savings, including but not limited to savings across all respective state departments and programs, and additional state-wide economic concerns and benefits.

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### **Action 3 - Research and advise on Persistent Barriers to Full Integration for People with Mobility Disabilities**

People with mobility disabilities are the largest category of people with disabilities in the United States, comprising an estimated 6.8% of all people with disabilities or just over 20 million people. Despite the nearly 50 years of federal nondiscrimination legislation requiring the removal of architectural and other physical barriers, those barriers remain prevalent and impede the ability of people with mobility disabilities to fully integrate into society. This report will focus on the barriers that people mobility disabilities confront today in the areas of public rights-of-way (sidewalks and other pedestrian routes); federally funded fitness and recreational facilities; and airline travel.

While the Americans with Disabilities Act required municipalities to develop an ADA transition plan within 3 years of the law's enactment in 1990, many municipalities have not done so, and for those who have adopted transition plans, those plans have not been maintained or updated.

In addition, municipal and park district owned and operated recreational and fitness centers, and fitness facilities on hospitals and college campuses, all of which receive federal financial assistance, and therefore subject to the mandates of Section 504 of the Rehabilitation Act of 1973 are largely inaccessible to persons with disabilities, and the overwhelming majority lack fitness equipment that can be utilized by persons who are blind or visually impaired and those with paralysis or mobility disabilities. Similarly, the thousands of private fitness facilities throughout the country, some of which receive federal financial assistance, like the YMCA, do not have physically accessible facilities or accessible fitness equipment.

The last segment of the report will focus on the horrors of airline travel for passengers who use wheelchairs. Every time a person with mobility disability who uses a wheelchair travels on an airplane they risk personal injury and the loss or damage of expensive mobility equipment, often leaving them stranded at their destinations. The fear and anxiety of flying for a person who uses a wheelchair often deters their use of the airlines as a mode of travel.

NCD will competitively source a cooperative agreement to conduct the research, which is overseen by a full-time senior attorney-advisor and informed by a small group of Council members.

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#### **Action 4 – Research and advise on equity through an Examination of Income and Assets Limitations Imposed by the Federal Government on People with Disabilities.**

The economic health of people with disabilities is, at best, abysmal. They are twice as likely to be unemployed and living in poverty as any other group in America. People with disabilities often face economic barriers that prevent them from realizing a path to self-sufficiency and, unfortunately, sometimes well-meaning government programs, that have not kept up with current disability law and trends, have contributed to this problem.

One of the most difficult barriers to economic self-sufficiency for people with disabilities is government-imposed limitations on earnings and assets for a person with disabilities, which if exceeded, triggers a loss or curtailment of a person's benefits, including critically needed support home and community-based services.

The fear of the loss of benefits, which is often referred to as the "income cliff," causes many people with disabilities to avoid competitive integrated employment and if they are employed in an integrated setting they often work a minimal number of hours to ensure that they do not exceed the earnings limits that would trigger a loss of their benefits. This then means that people with disabilities are unlikely to be eligible for (or if eligible, may forego) any type of promotions, job growth or job security that can lead to greater income and a better potential economic future.

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### **Action 5 – Research and advise on health equity through examination of the Absence of People with Disabilities in Clinical Trials**

People with disabilities are at a higher risk for numerous health conditions compared to the general population. For example, clinical trials for Alzheimer's exclude people with Down syndrome, even though approximately 90% of people with Down syndrome will develop Alzheimer's disease or dementia by age 55.[1] Not only are people with disabilities (PWDs) at higher risk for many conditions and diseases compared to the general population, disability itself can change the presentation and/or management of a disease, and clinicians need to be aware of these differences.

The exclusion of PWDs in research has been well-documented. The exclusion of people with psychiatric, substance use, and intellectual disabilities is especially prevalent. Eligibility criteria affecting people with disabilities included exclusions for psychiatric (68 percent), substance use (62 percent), HIV or hepatitis (53 percent), cognitive or intellectual (42 percent), visual (34 percent), hearing (10 percent), mobility (9 percent), long-term care (6 percent), and speech and communication (3 percent) disability-related domains. Documented justification was provided for only 24 percent of these exclusions.



Researchers who receive federal funding also have a legal obligation not to discriminate against PWDs under Section 504 of the Rehabilitation Act. Whether the exclusion of PWDs in clinical trials is explicit or implicit, such exclusion is a possible violation of federal laws.

The final report will provide recommendations and promising practices to increase the acceptance and participation rates of people with disabilities in clinical trials.

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### **Action 6 – Research and advise on the longstanding administrative exclusion under federal employment tax law for people with disabilities in congregate work settings**

In most circumstances, the Federal Insurance Contributions Act (FICA) generally requires employees and employers to pay taxes on all “wages” employees receive, 26 U.S.C. §§ 3101(a), 3111(a), and defines “wages” to include “all remuneration for employment,” § 3121(a). FICA defines “employment” as “any service . . . performed . . . by an employee for the person employing him,” § 3121(b). Unlike other federal employment laws like the Fair Labor Standards Act's definition of employee however, FICA's definition of “employee” applies an independent analysis under common law rules in determining the employer-employee relationship and the status of an employee. § 3121(d)(2). Likewise, the Social Security Act, which governs workers' eligibility under the OASDI program, contains a materially identical employee analysis to I.R.C. § 3121(d)(2). 42 U.S.C.S. § 410(j)(2), also citing to common law rules to determine whether an employer-employee relationship exists.

Since a 1965 Revenue Ruling, the Treasury Department has consistently determined that people with disabilities in congregate work settings are not “employees” for federal employment tax purposes. In 1969, the Commissioner of the Social Security Administration issued a ruling that adopted a materially identical exclusion to the one used by the IRS and determined that workers with disabilities in congregate work settings could not be considered employees of the facility until after completing its rehabilitation program and meeting common law employment rules. SSR 69-60. Since these 1960s rulings, both SSA and the Internal Revenue Service (IRS) have maintained that an individual participating in a congregate work setting's training or rehabilitation program could not be considered an employee of the workshop. Accordingly, the compensation received from the congregate work settings could not be considered wages for Social Security coverage

purposes and not subject to FICA taxes. Both agencies further held that only after completing the facility's training or rehabilitation program could a person be considered an employee of the congregate work setting.

The purpose of this report is to study the legal implications that may result from the Treasury Department's 1965 analysis of the employment status of people with disabilities in congregate work settings that may result in dueling classifications for federal employment tax purposes that allows employers to classify workers as a "client under a rehabilitation program" and not employees. It will also look at other federal employment laws that may have adopted the Treasury Department's analysis that may include the National Labor Relations Act and the Employee Retirement Income Security Act of 1974. NCD expects this report to make recommendations to the Department of Treasury (and other federal agencies) to re-evaluate its regulations and past rulings to be consistent with current disability policy.

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