



National Council on Disability

AGENCY EQUITY ACTION PLAN SUBMITTED TO DPC AND OMB

Please email any questions to equity@omb.eop.gov.

(1) **Executive summary** (Max length: One page)

- Agency name and mission

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.

- Summary of Action Plan

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:

- 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); and
- 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.

(2) **Summary of early accomplishments** (Max length: One page)

- Please highlight any equity-related achievements or successes (e.g., innovative stakeholder engagement, notable changes in policies or operations, new partnerships, etc.) since EO 13985 was released on January 20, 2021.

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.
- 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 research 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.
- Started collaborating with the Administration on Community Living to update NCD's 2003 Native American Toolkit, which is called "Understanding Disabilities in American Indian and Native Alaskan Communities" via a Memorandum of Understanding between NCD and the National Indian Council on Aging.
- Finished work on a policy project set for an early 2022 release regarding 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, devised a comprehensive proposed framework to ensure health equity for persons with disabilities, which we have briefed federal agencies and congressional offices on for feedback.
- 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 CRCL's role to ensure 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.

- Released research and advice to policymakers on 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.
- 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.
- 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.
- 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 (NIMHHD) and the Agency for Healthcare Research and Quality (AHRQ) that people with disabilities be designated as a “health disparity population,” as the NIMHHD is authorized to do after consultation with the AHRQ under 42 U.S.C. Section 285t(d)(1).

(3) Equity action plan (*Max length PER ACTION: Two pages*)

Please clearly identify **three to five** actions that your agency plans to undertake and list them **in order of priority**; provide evidence-based reasoning for selection; and outline high-level elements of implementation. (Actions should address the institutional resources available to offices responsible for advancing **civil rights** pursuant to Section 5(d) and **procurement and contracting** pursuant to Section 7(a) of EO 13985 but may also focus on other significant priorities identified by the agency regardless of whether they were included in the agency’s equity assessment.)

For **each action**, please include:

A. Barrier to Equitable Outcome(s)

- *Describe the barrier you are trying to address.*
- *Specify the program, policy, or regulation that contributes to this barrier.*
- *Indicate which populations are most impacted by this barrier.*
- *List the evidence indicating that this barrier meaningfully impacts full and equal participation.*

B. Action and Intended Impact on Barrier

- *Describe the actions the agency will take to eliminate/reduce the barrier.*
- *Why did you prioritize these actions?*
- *Indicate how the actions are expected to result in reducing or eliminating the barrier to equitable outcomes. If not identified above, please indicate what evidence supports this connection.*

C. Tracking Progress

- *Describe what factors you will use to determine whether the agency action(s) has eliminated or substantially reduced the barrier to equitable access identified above in the near- to mid-term (2-4 years out).*
- *Indicate what success might ultimately look like in the long-term (5-8 years out).*

D. Accountability

- *Describe how the agency will hold itself accountable to implementing this action. Consider potential internal and external mechanisms (e.g., aligning with the Agency Strategic Plan and/or other public-facing documents, embedding equity-related goals in performance plans, holding virtual town halls, etc.) and how and when the agency will communicate progress to stakeholders.*

Action 1 – Research and advise 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 will gather data and evidence to identify 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 will offer recommendations on how to mitigate the impact of the increased frequency of extreme weather

events and environmental injustice on persons with disabilities. This report will discuss 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.

NCD has allocated \$185,000.00 of its policy budget to this project and will use a competitively sourced cooperative agreement with an outside entity to complete the research, which is overseen by a full-time senior attorney-advisor and informed by a small group of appointed Council members.

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 – Research and advise on health equity through examination of states' use of Quality Adjusted Life Year (QALY) Based Cost-Effectiveness Reports to Inform Medicaid Coverage for Prescription Drugs

The QALY is a broad population-based cost and cost-effectiveness analyses developed by health economists to measure and compare the benefits of healthcare interventions for cost effectiveness which is used to allocate health care resources. The use of QALYs in health-care coverage decisions, rather than metrics that consider specific patient needs and heterogeneity, have resulted in discrimination against people with chronic illnesses and disabilities because QALY-based metrics often conclude that the treatments they need are too expensive, resulting in delayed, restricted, and denied healthcare. There are serious ethical concerns with how QALYs are developed and used. QALYs fall short in measuring health preferences for patients with chronic diseases and disabilities and place greater value on years lived in full health, or on interventions that prevent loss of perfect health while discounting gains in health for individuals with chronic illnesses. QALYs require valuing one individual's life over another's, which may result in only providing healthcare to those that are deemed to have the greatest benefit from a treatment, such as a person who will fully recover and return to perfect health. Additionally, people with disabilities may enjoy a comparable quality of life to non-disabled individuals but may face a shorter life expectancy compared to someone without their condition. Because QALYs are assigned by both quality as well as quantity of life, an incremental QALY assessment would prioritize providing treatment to a nondisabled person with a longer theoretical

life expectancy over a person with a disability. The purpose of this report is to look at State's use of ICER's QALY-based cost-effectiveness reports or international drug prices to inform coverage of prescription drugs in their Medicaid programs.

It will describe how many States are using ICER QALY-based cost studies or referencing international prices; how this information is being used, e.g., as a benchmark or cost-threshold, and if this has resulted in restricted access to prescription drugs. The report will gather evidence that shows whether reliance on this information is delaying access to or denial of coverage of necessary drugs and treatments for chronic illnesses. It will also describe methodological alternatives to QALYs that consider patient values and preferences. It will make findings and make specific recommendations to Congress, Federal Government, and states to address the findings. NCD competitively sourced a \$65,000 cooperative agreement a contractor to complete this research, which is overseen by a full-time senior attorney-advisor and informed by a small group of appointed Council members.

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Action 3 – Research and advise 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

Approximately 14 million Americans of all ages need long-term services and supports; 40% adults who need these supports are younger than 65 years old. LTSS include a wide range of services and supports that assist older individuals and people with disabilities with self-care and activities of daily living. Medicaid is the primary payer of formal LTSS, financing approximately 62% of LTSS costs. Almost all individuals who need LTSS want to live at home. The financial savings of supporting people in the community instead of congregate settings has long been established. According to the Kaiser Family Foundation, the annual cost of care at a congregate facility, like a nursing home, is \$91,250 in 2015, compared to \$45,800 for a home health aide and \$18,000 for adult day services. Americans are estimated to save \$43,947 annually per individual served in the community instead of a congregate care setting. The US Supreme Court's Olmstead decision and federal programs over the last decade have contributed to

significant progress and in shifting from services in nursing homes and other institutional settings to home and community-based services (HCBS). Nationally, over 56% of total Medicaid LTSS spending is devoted to HCBS. Despite this investment, Americans with disabilities less than 30 years old make up the fastest growing nursing home population and people with disabilities ages 31 to 64 comprise 14% of the nursing home population. While the shift from institutions to community settings is promising for both societal and fiscal gains, it didn't happen quickly enough to save the thousands of people with disabilities who died of COVID-19 in in congregate settings.

The devastation of COVID-19 has been felt worldwide, but its impact has not been evenly distributed. This public health emergency brought new urgency to moving people out of congregate settings and into the community. The criminal justice system recognized the risk of massive loss of life and responded by releasing more than 100,000 people from federal and state prisons between March and June 2020. Despite even greater risks and eventual costs, systems responsible for the institutionalization of people with disabilities did not mirror this response. People with intellectual and developmental disabilities (ID/DD) have been more likely to become infected with COVID-19, need hospitalization, and die. A 2021 review in the *New England Journal of Medicine* stated, "having an intellectual disability was the strongest independent risk factor for presentation with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality". People with ID/DD living in congregate care settings, including nursing homes and group homes, were at an even greater risk for severe COVID-19 outcomes¹. By November 2020, more than 100,000 people with disabilities in long-term care facilities had died due to COVID-19. The problem of institutionalizing people is going from bad to worse. The unnecessary deaths of people with ID/DD during the COVID-19 pandemic must initiate major, irreversible systemic changes to move people with disabilities out of institutions and into their communities.

This report will identify failed aspects of the United States HCBS system, which contributed to the unnecessary deaths of more than 100,000 people with disabilities from COVID-19 in congregate care settings, including group homes, Intermediate Care Facilities, and nursing homes, and propose preliminary solutions to bolster this critical infrastructure at a time of its greatest need. NCD allocated \$65,000.00 to a contractor with Cincinnati Children's Hospital Medical Center via a single source cooperative agreement to work with NCD on completing this research, which is overseen by a full-time senior attorney-advisor and informed by a small group of appointed Council members.

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¹ Landes, Scott D., Margaret A. Turk, Margaret K. Formica, Katherine E. McDonald, and J. Dalton Stevens. "COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State." *Disability and Health Journal* 13, no. 4 (2020): 100969.

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Action 4 – Research and advise on health equity through examination of ways to incentivize oral healthcare providers to treat patients with intellectual and developmental disabilities (I/DD) through Medicaid

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.

Since 2017, NCD has focused on achieving improved access to oral healthcare for people with intellectual and developmental disabilities. Through analysis conducted by NCD preceding this project, NCD found that there would be a return-on-investment for states that do not currently provide non-emergency Medicaid oral healthcare coverage for people with I/DD through healthcare cost savings that would largely exceed the cost of providing preventive services through Medicaid. In 2017, with publication of its policy brief, *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities*, NCD outlined areas through which access to improved oral health can be achieved. Those areas included required training for dental students to manage treatment of patients with I/DD, and changing the American Dental Association’s *Code of Professional Conduct* to stipulate that dentists may not deny treatment to a

patient based on the patient's disability status and referring the patient to a provider able to provide treatment when necessary.

Many of the policy recommendations NCD has made in the space of oral healthcare for patients with I/DD have been implemented. The American Dental Association has revised its professional code to state that a provider may not deny care to a patient based on a patient's disability, and the Commission on Dental Accreditation now requires all US dental schools to train students to manage treatment of patients with I/DD. 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. NCD is competitively sourcing a cooperative agreement for this work in the amount of \$100,000.00 with an outside contractor, which will be overseen by a full-time senior attorney-advisor and informed by a small group of appointed Council members.

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Action 5 – 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.

A review of IRS Private Letter Rulings (PLRs) shows that over several years, the agency issued a series of decisions on behalf of “sheltered workshops,” which was used to re-classify workers with disabilities as “clients” and deny their employment status. These rulings may have been used to retroactively re-classify the compensation they received as no longer being “wages” subject to FICA taxes and despite any employment determinations made by the Department of Labor. Following this trend, sheltered workshops may have turned to the Department of Justice to settle lawsuits against the IRS and claim FICA tax refunds claiming their work settings were similar to other workshops that previously received PLRs.

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. NCD is competitively sourcing this cooperative agreement in the amount of \$100,000.00 with an outside contractor, which will be overseen by a full-time NCD legislative affairs specialist and informed by a small group of appointed Council members.

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