

INTRODUCTION FROM THE CHAIRMAN

The National Council on Disability (referred to herein as "NCD" or "the Council") is an independent, nonpartisan federal agency that provides the President, his Administration, the U.S. Congress and the heads of federal agencies with timely analysis and recommendations to advise policy development, revision, implementation, and enforcement efforts to enhance the quality of life for all Americans with disabilities and their families. The Council's purview is expansive and not limited to a single disability subpopulation, age, or topic matter. Accordingly, our research traverses a true diversity of issues, attempting always to be timely in response to current events as well as in anticipation of emerging concerns of people with all types of disabilities throughout the United States and in our territories.

The Council presents this budget justification for FY24, requesting a total budget authority of \$4,000,000. These resources will be applied to the furtherance of our mission to advise the President, Congress, and other federal agencies regarding federal policies and the impact on people with disabilities.

As we present this year's budget justification, as it was during our prior year submission, the challenges affecting people with disabilities throughout the country and in our territories remain formidable and exacerbated due to the global pandemic – a pandemic that has disproportionately affected the health and well-being of persons with disabilities, who remain vulnerable to the extreme effects of the virus given decades of neglect in meaningfully addressing the chronic and profound health disparities between persons with disabilities and those without, and decades of neglect in addressing systemic and pervasive barriers to accessible healthcare.

It is for those reasons that the Council's focus during Fiscal Year 2024 will remain in large part on addressing healthcare barriers and the breadth of issues associated therewith. And 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" which directed agencies to take a whole-of-Government approach to increase resilience to the impacts of climate change and protect public health, NCD

intends to release and brief on a report that addresses the impacts of extreme weather events on the lives of people with disabilities, advising Congress and the Administration on how they can effectively take a whole-of-government approach to addressing those impacts.

Throughout all the work we undertake, we will endeavor to work closely and collaboratively with federal partners and legislators on commitments expressed in the President's disability plan, even as we always advise for even greater efforts.

Our budget submission for Fiscal Year 2024 facilitates the Council's ability to continue to address pressing issues confronting people with disabilities in the form of advice and counsel to policymakers, and in so doing, serve as the voice of people with disabilities within the Federal Government.

Respectfully,

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Andrés J. Gallegos Chairman

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AGENCY OVERVIEW

Agency Mission

The mission of the National Council on Disability is to be a trusted advisor regarding the impact of federal policies on the lives of people with disabilities to the President, U.S. Congress, and other federal agencies, by developing policy recommendations; reviewing existing policies' effects on the quality of life of people with disabilities; and by engaging policymakers and responding to their requests for assistance accurately, efficiently and without bias.

The National Council on Disability (referred to herein as "NCD" or "the Council") is an independent, nonpartisan federal agency that provides the Administration and the U.S. Congress with timely analysis and recommendations to advise policy development, revision, implementation, and enforcement efforts as they have impact on the lives of people with disabilities across America. Our purview is not limited to a set policy area or subgroup of disabled Americans, so our advice is not siloed at the exclusion of others' interests. The Council provides advice that thoughtfully considers the diverse needs of our core constituency, which varies greatly by type and severity of disability. NCD is critical in preserving and strengthening the impact of the Americans with Disabilities Act (ADA) in our nation's policies and programs. The Council is inextricably intertwined with the ADA and its history.

First established as an advisory council within the Department of Health, Education, and Welfare in 1978, and then placed within the Department of Education, NCD became an independent federal agency in 1984. The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed the National Council on Disability into an independent agency and required NCD to provide advice to Congress and the Administration. In 1986, NCD recommended enactment of an Americans with Disabilities Act (ADA) and drafted the first version of the bill which was introduced in the House and Senate in 1988. Since enactment of the ADA in 1990, NCD has continued to play a leading role in crafting disability policy, and advising the President, Congress and other federal agencies on disability policies, programs, and practices. Changes were also made to the Council by the Rehabilitation Act Amendments of 1992 and 1998, the Education of the Deaf Act Technical Amendments of

1993, and most recently, by the Workforce Innovation Opportunity Act (WIOA) of 2014 (Public Law 113-128).

Upon its establishment as an independent agency, Congress charged NCD with a new mandate to review all existing federal policies and programs. Two years later, the Council delivered on that charge with its path breaking report, *Toward Independence*, which called for enactment of a federal disability civil rights law. The Council later offered the first draft of that civil rights law in 1988. After President George H.W. Bush signed the ADA into law, the mission of the Council was amended to reflect the national disability policy goals now enshrined in the ADA.

NCD serves a unique role among federal agencies because its mission reflects the breadth and diversity of the disability community itself. In its authorizing statute, the Council's duties are extensive and belie the Council's limited financial and human resources. In FY 2022, the Council had a \$3.5 million annual appropriation to support its mission of gathering information and reviewing and evaluating on a continuing basis all "policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies...," and "all statutes and regulations pertaining to federal programs which assist such individuals with disabilities..."

COUNCIL STRUCTURE

The governing body of the Council is comprised of nine members (five presidential and four congressional appointees), including a Chair, whom the President designates; and a Vice-Chair, appointed by the Chair. Congressional appointees are appointed by each of the following: the Speaker of the House, the House Minority Leader, the Senate Majority Leader, and the Senate Minority Leader. Each council member may serve a three-year term, with the possibility of a second term. Council members serve until a replacement appointment occurs; therefore, terms can extend beyond six years.

Council members are special government employees (SGE) who live across the country and serve in a part-time capacity. Each appointee brings a unique perspective informed by varied personal and professional experiences. Council members are people with disabilities, disability service providers, parents or family members of people with disabilities, or other people who have substantial knowledge of or experience with disability policies and programs. Council members are appointed to represent people with disabilities, national organizations concerned with disabilities, providers and administrators of services to people with disabilities, people engaged in conducting medical or scientific research related to disabilities, business concerns and labor organizations. By statute, a majority of the members of the Council are to be people with disabilities and are to be broadly representative of minority and other individuals and groups. Currently, eighty-nine percent of the current council members are people with disabilities. Eighty-two percent of full-time staff are people with disabilities.

Every year, the Council and staff propose and advance new policy projects based upon current events, national trends, respective areas of expertise, suggestions from policymakers, and anticipated legislative reauthorizations or regulatory activities. The Council deliberates and ultimately votes on upcoming priorities. In response to the vote, and in consideration of the Council's budget, statements of work are developed to undertake the research approved by the Council.

To fulfill the mission of the National Council on Disability, the Chair appoints members to advise on commissioned policy priorities within a subcommittee structure. These subcommittees are comprised of no more than four council members and a full-time professional staff member who manages the work of the project, drafts portions of policy advice based upon council members' discussions and research, and who acts as a Contract Officer Representative (COR), or Agreements Coordinator, for any supplemental data provided to a project from a contracted researcher. Once each policy project yields a final draft product, it is shared with the entire Council for review, discussion, refinement, and ultimately, a vote of approval by council members. Once approved, professional staff work with a professional editor on final edits and report layout before dissemination of the final report, including its policy recommendations to the President, Congress, other federal agencies and all interested parties.

When opportunities or circumstances warrant immediate response to proposed legislation or regulations, including when the Council is requested directly by policymakers for such input, the Council provides brief, nimble responses based upon the Council's existing body of research and recommendations to ensure the needs of people with disabilities are discussed and included present in new legislation and policies.

The Council's vote is required to approve the Council's annual budget and spending plan as well as all published research, papers, and formal opinions published in the name of the Council Members, except that the requirement of a vote for changes to the budget may be suspended consistent with the powers of the Executive Committee. Professional staff provides a status of funds and updates on policy projects to the Executive Committee approximately monthly. The Council is provided updates no less than once per quarter as part of the quarterly business meetings of the Council.

In addition to projects that the Council votes to commence during the budget cycle, NCD continues to brief and advise on past work and meet with policymakers to ensure that NCD's recommendations are known and understood.

NCD is a respected resource within the Federal Government and beyond on all disability policy issues.

ORGANIZATIONAL STRUCTURE

The bylaws of the Council delegate the power, authority, and responsibility to the executive director to supervise and direct the day-to-day business and management of the Council, including decision-making processes and allocation of staff resources to assist presidentially and congressionally appointed members in fulfilling their duty to advise on policy priorities that will improve the lives of all Americans with disabilities.

A small, dedicated full-time staff support the work of the council members, with its physical office located in Washington, DC. The executive director is responsible for hiring technical and professional employees to assist the Council to carry out its duties and is accountable for assignment of staff duties. (*See* Appendix C, Organizational Chart).

The duties of the professional staff include:

- Analyzing federal laws, regulations, programs, policies, and case law precedent; and proposing and developing policy positions that have a national, state and international impact on the lives of people with disabilities;
- Monitoring congressional activity on issues critical to the disability community and cultivating and maintaining effective working relationships with stakeholders at the federal, state, and local levels; and
- Providing critical staff support and monitoring the Council's finance and accounting, information technology, and human resources management.

PERFORMANCE

STRATEGIC FRAMEWORK, FISCAL YEAR 2022 - 2026

The Council's budget submission is submitted for the second fiscal year of its five-year strategic plan. The plan seeks to reflect goals and objectives approved by the Office of Management and Budget and prioritized by the Council's constituency to focus on the most pressing needs of the disability community in furtherance of the goals of the Americans with Disabilities Act; optimize operational efficiency and accountability; and

pursue mission-critical activities consistent with the Administration's priorities and directives.

The Council evaluates its progress towards fulfillment of its goals and objectives by conducting program evaluations prior to implementation – formative needs evaluation, periodically and ad hoc; formative process evaluation; and at the end of each, summative outcome and impact evaluation.

OBJECTIVES, STRATEGIC RESULTS AND PLANNED ACTIVITIES

NCD has a unique mission among federal agencies as it is charged with reviewing all programs and policies across the Federal Government, not merely one aspect of policy affecting people across all types of disabilities or all policy areas affecting only one subpopulation of people with disabilities. With that unique and far-reaching mission in mind, the Council's strategic goals for FY 2022 – 2026 include the following:

- Goal 1 Develop new disability policy recommendations with a particular emphasis on issues of healthcare equity, employment, and the inclusion of traditionally underserved communities.
- Goal 2 Review and analyze both proposed and existing federal policies' impact on people with disabilities.
- Goal 3 Engage policymakers of both the Administration and Congress and respond to their requests for assistance accurately and efficiently.
- Goal 4 Gather information from subject matter experts and members of the disability community both of Washington, DC, and nationally, to help inform policymakers' work.
- Goal 5 Enhance agency operational and programmatic internal controls to effectively service execution of statutory duties.
- Goal 6 Recruit, retain, and develop a highly qualified professional staff in order to effectively service execution of statutory duties.

GOAL 1 OBJECTIVES, STRATEGIC RESULTS AND PLANNED ACTIVITIES

GOAL 1: Develop new disability policy recommendations with a particular emphasis on issues of healthcare equity, employment, and the inclusion of traditionally underserved communities.

- Develop recommendations that help foster healthcare equity and accessibility for people with disabilities in a manner consistent with self-determination through a series of health equity legislative proposals or a combination of executive, administrative, or legislative action.
- 2. Develop recommendations that enhance equal opportunity for people with disabilities to achieve economic self-sufficiency through the elimination of the Medicaid benefits cliff and a national Medicaid buy-in program.
- 3. Provide recommendations that promote job growth for people with disabilities through the Small Business Administration (SBA) 8(a) Business Development Program.
- 4. Develop recommendations to address the concerns and issues uniquely associated with people with disabilities within tribal communities.
- 5. Develop recommendations to address the disparate treatment of citizens with disabilities residing in Puerto Rico (and disabled citizens in other U.S. territories) under certain federal programs in contrast to their counterparts residing on the mainland.
- Develop recommendations to improve Home and Community Based Services and transition from institutionalized settings to community living for people with disabilities based on widespread deaths of institutionalized people with disabilities during the COVID-19 pandemic.
- Develop recommendations to advance the testing and use of alternatives to the Quality Adjusted Life Year (QALY) in valuing prescription drugs and other healthcare interventions.
- 8. Provide recommendations to ensure that federal college crime surveys include disability as a demographic.
- 9. Develop recommendations regarding inclusion of people with disabilities in clinical trials.
- 10. Develop recommendations regarding federally imposed income and asset limitations imposed on people with disabilities.

- 11. Develop recommendations on the ethical advancement of fetal medicine and genetic technology.
- 12. Develop a financial "score" for what it would cost the Federal Government if people with I/DD in the US were designated as a medically underserved population (MUP) under the Public Health Service Act.
- 13. Develop recommendations to address the legal implication of a long-standing tax exemption for people with disabilities working in congregate settings (or sheltered workshops) which creates dueling classifications that conflict and undermine other federal employment laws regarding the employment status of people with disabilities, the work they perform, and the compensation they receive.
- 14. Develop recommendations to address the persistent barriers to full integration for people with disabilities, including airline travel and wheelchair securement systems.

In furtherance of Goal 1, the Council accomplished the following in FY 2022:

- Continued to update and amend NCD's <u>Health Equity Framework</u> to reflect information gleaned from ongoing stakeholder engagements; and meet and discuss the framework with the National Institute on Minority Health and Health Disparities; the Joint Commission; Liaison Committee on Medical Education; the Agency for Healthcare Research and Quality; Health Resources and Services Administration; the Administration on Community Living; the National Institute on Disability, Independent Living, and Rehabilitation; the Administration for Community Living; the Centers for Medicare and Medicaid Services; and others.
- As requested, provided technical assistance and suggestions for improvement on proposed bill language to several congressional offices contemplating pursuit of legislation on an array of topics.
- <u>Advised the Small Business Administration</u> on adding people with disabilities to the groups that are presumptively eligible to participate in the SBA'S 8(a) business development program.
- Completed a research report on the weaknesses in home- and community-based services (HCBS) and barriers to transition of people with disabilities to community living, highlighting the serious deficiencies that contributed to the disproportionate amount of deaths of people with disabilities living in institutionalized settings during the COVID-19 pandemic.
- Completed a research brief on value assessment methods for use in healthcare that do not rely on the QALY or that apply it in a manner that lessens its discriminatory aspects/effects on people with disabilities and chronic illnesses.
- In addition, several House and Senate offices relied on NCD's policy advice related to healthcare in requests they sent to the House and Senate Labor, HHS, and related agency Appropriations subcommittees, which are reflected in the Committee report language¹, including:

¹ <u>https://www.congress.gov/117/crpt/hrpt403/CRPT-117hrpt403.pdf</u>

From Enforceable Accessible Medical Standards: The Committee is aware of a recent NCD report entitled "Enforceable Accessible Medical Equipment Standards—A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities," which identified inaccessible medical equipment among the reasons for the susceptibility of people with disabilities to experience substandard health care, citing numerous studies documenting access barriers involving medical equipment and the health disparities experienced by millions of people with disabilities. NCD raised concerns that people with physical disabilities often postpone or delay care due to the inability to get onto exam tables and other diagnostic equipment and have to search for facilities that have such equipment. Relatedly, NCD has recently advised Congress and the Administration regarding the nexus between the lack of disability clinical care training for health care professionals and the well-documented health disparities experienced by people with disabilities. Accordingly, the Committee strongly encourages the Centers for Medicare and Medicaid Services to require disability clinical care training and the availability of accessible medical and diagnostic equipment into its conditions of participation for Part A and Part B providers.

From NCD's <u>*Health Equity Framework*</u>: The Committee strongly encourages the Secretary, acting through the Health Resources and Services Administration, to implement 42 U.S.C. 293(e), to develop a grant-based program in collaboration with the NCD, professional societies, licensing and accreditation entities, health professions schools, and experts in minority health and cultural competency, prevention, and public health and disability groups, and community-based organizations to expand upon the National Initiative In Developmental Medicine: Draft Curriculum, which targets a patient population of adults with intellectual and developmental disabilities, to include disability clinical care competency training inclusive of all disability patient subpopulations (e.g. Deaf, blind, mobility disabilities, etc.).

From <u>The Danger of Physician Assisted Suicide Laws</u>: The Committee strongly encourages the HHS Office of Civil Rights (OCR) to clarify that all HHS suicide prevention grants and services must comply with existing disability rights laws,

including the ADA, and Sections 504 and 508 of the Rehabilitation Act, including the provisions requiring accessible communications, so that all videos, documents, and other products ensure access to persons with disabilities. In addition, the Committee encourages OCR to recommend that hospitals create a disability ombudsperson position who is authorized to facilitate communication between healthcare providers and patients with disabilities or their proxies and advocate on the patient's behalf, when required, to ensure that all clinical and LTSS options and choices are made available.

In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

- Advise policymakers on the need to include people with disabilities in clinical trials.
- Advise policymakers on the barriers imposed on people with disabilities as a result of income and asset limitations in federal program and benefit eligibility requirements. Advise policymakers on the rapidly advancing field of fetal medicine and genetic technology and the implications for people with disabilities.

GOAL 2 OBJECTIVES, STRATEGIC RESULTS and PLANNED ACTIVITIES

GOAL 2: Provide perspectives and analysis on existing federal policies' impact on people with disabilities.

- 1. Provide findings and recommendations regarding disaster and healthcare emergency relief planning and responses with respect to the rights of people with disabilities.
- 2. Provide recommendations concerning proposed policies of healthcare equity.
- 3. Provide recommendations concerning proposed policies of pandemic preparedness, including how home and community-based services HCBS have been impacted.
- 4. Provide analysis and recommendations concerning economic opportunities for people with disabilities.

- Provide recommendations concerning an increase in the oral health Medicaid reimbursement rate for people with intellectual and developmental disabilities as a means of saving costs long-term.
- 6. Provide recommendations concerning civil rights enforcement.
- 7. Advise policymakers on specific tax exemptions that prevent people with disabilities from attaining employment for federal employment tax purposes.
- 8. Provide analysis and recommendations on the need to include people with disabilities in clinical trials.
- Provide analysis and recommendations regarding the impact of income and asset limitations imposed on people with disabilities through federal program and benefits eligibility requirements.

In addition to the projects that the Council approves for commencement of work and dissemination in Fiscal Year 2024, the Council continues to disseminate its work and meet with policymakers regarding its existing reports and position letters that address proposed and existing legislation. For example, in FY22, NCD met with several House and Senate offices to discuss the release of NCD's report, Disparate Treatment of Puerto Rico Residents with Disabilities in Federal Programs and Benefits, and its recommendations to expand federal program benefits to the residents in Puerto Rico. In addition to the Committees of jurisdiction over U.S. Territories, NCD discussed the report and recommendations with members of the Hispanic Caucus and Hispanic Conference. Through these meetings, policymakers asked about NCD about ways states blend funding under the Individuals with Disabilities Education Act (IDEA) and Medicaid to improve services for children with disabilities. NCD provided them with information from our 2018 IDEA Series: Broken Promises: The Underfunding of IDEA when providing response. NCD is currently serving on a White House interagency committee looking at economic resilience in Puerto Rico and assisting other federal agencies on how the disability community is impacted.

As another example, as Congress has continued to pursue the goal of lowering prescription drug prices, our 2019 report, <u>Quality-Adjusted Life Years and the Devaluation</u> <u>of Life with a Disability</u>, which outlines concerns with the use of QALY-based value assessments, NCD has continually <u>brought to policymakers' attention</u> the issues raised in Page **15** of **52**

the report. Additionally, we weigh in with technical advice as well as overarching policy principles with our federal colleagues on disability-related regulatory proposals that impact people with disabilities when they arise (such as CMS's consideration of national coverage determinations regarding seat and standing elevation systems on power wheelchairs or HHS OCR's pursuit of a proposed rule regarding disability nondiscrimination in health care); and with congressional staff on general legislative proposals that impact people with disabilities, as well as disability-specific legislation that is introduced.

In furtherance of Goal 2, the Council accomplished the following in FY 2022:

- <u>Advised</u> and continued to meet with the National Institute on Minority Health and Health Disparities (NIMHD) and the Agency for Healthcare Research and Quality (AHRQ), on decades of health research on people with disabilities in support of a designation of people with disabilities as a "health disparity population."
- Began a report that examines the legal implication of a long-standing tax exemption for people with disabilities working in congregate settings (or sheltered workshops) which creates dueling classifications that conflict and undermine other federal employment laws regarding the employment status of people with disabilities, the work they perform, and the compensation they receive (anticipated release Spring 2022).
- Developed a report that examined the state of the nation's HCBS in place prior to and during the pandemic that contributed to the inability of residents with I/DD to transition to lesser-density community housing options (anticipated release Fall 2022).
- Developed a report on the impacts of increased extreme weather events on the lives of people with disabilities (release date uncertain).
- Finalized and released a <u>report</u> on the disparate treatment of Puerto Ricans with disabilities in federal programs.
- Finalized and released a progress report on the impact the COVID-19 global pandemic has had on people with disabilities.
- <u>Advised FBI Director Wray</u> concerning the National Use of Force Data Collection program, which collects incidents data from police organizations across the US to

identify which police organizations used excessive force and could thus benefit from remedial intervention.

- Developed and released a <u>health equity framework</u>, which includes, among other things, consideration of Special Medically Underserved Population designation; and recommendations concerning disability competency training of medical professionals, improved data collection, incentives for healthcare providers to treat patients with disabilities, and accessible medical equipment.
- Provided <u>comments</u> on subminimum wages in response to the Federal Register notice: Prohibition on the Payment of Subminimum Wages Under 14(c) Certificates as a Qualification for Participation as a Nonprofit Agency Under the Javits Wagner O'Day Program.
- <u>Continued to advise</u> the Joint Commission (on hospital accreditation) concerning disability competency training of medical professionals and provided them with related recommendations concerning health equity for people with disabilities.
- Created a Tribal Coordination EO/Tribal Lands toolkit to update NCD's 2003 report "Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide" (anticipated Spring 2023 release).
- Advised the Department of Education on the need for disability competency training of medical students.
- <u>Advised</u> the Office of the National Coordinator for Health Information Technology (ONC) through a series of meetings on the need to gather disability functional status in electronic health records.
- Developed and released <u>Medicaid Oral Health Coverage for Adults with Intellectual and</u> <u>Developmental Disabilities</u> regarding health care issues faced by people with ID/DD, recommending an increase in Medicaid coverage for people with intellectual and developmental disabilities (I/DD) to ensure preventive care is available and to avoid preventable illness and in emergency room care for untreated dental problems.

- Served on HHS' National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) to advise the Secretary of Health and Human Services on actions HHS can take before, during, and after disasters and emergencies to meet the unique needs of individuals with disabilities.
- Worked with the Federal Emergency Management Agency (FEMA)'s Office of Disability Integration and Coordination to form a federal working group to work on more comprehensive emergency management guidance among multiple federal agencies and had recurring meetings with FEMA on emergency preparedness and disaster relief to advise FEMA on disability stakeholder concerns.
- Participated in National Institute of Health (NIH)'s monthly meetings on NIH's development of accessible home diagnostic tests for consumers with limited vision or blindness and those with limited or no dexterity.
- Developed a <u>research brief</u> on alternatives to the Quality Adjusted Life Year
- <u>Provided a response</u> to CMS's Request for Information on Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities, regarding organ transplant discrimination experienced by people with disabilities throughout the organ transplantation process.
- Sent an <u>advisory letter</u> and met with the Administrator of the SBA Administrator regarding the addition of people with disabilities to the 8(a) Business Development Program presumed group list. NCD provided research and findings to support the request.
- Began development of a <u>report</u> on the impact of the Supreme Court decision in *Cummings v. Premier Rehab Keller, P.L.L.C.,* which held that that emotional distress damages are not recoverable in a private action to enforce either the Rehabilitation Act or the Affordable Care Act (released in January 2023).
- Held a <u>virtual policy roundtable</u> with over 300 attendees, including CMS and congressional staff, to discuss CMS' National Coverage Determination of seat and standing elevation systems, featuring perspectives and research from academics, doctors, patients, and advocates.

- <u>Advised the Departments of Justice and Education</u> on recommendations regarding the need to include disability as a demographic in federal research surveys regarding campus crime and campus sexual assault in light of the fact that nongovernment studies have found that 1 in 3 college students with disabilities report experiencing an assault on campus.
- Advised the Department of Education Office for Civil Rights on ways to improve current regulations to assist students with disabilities, specifically addressing needed changes to Section 504 regulations.
- Advised the Department of Health and Human Services (HHS) Office for Civil Rights on its draft changes to HHS' Section 504 regulations.
- Participated in HHS' Long COVID Coordination Council meetings and contributed to the development of an interagency document that provides information to the public about long COVID and resources for those who have long COVID, titled Services and Supports for Longer-Term Impacts of COVID-19.
- Participated in Amtrak quarterly meetings regarding its efforts to make Amtrak stations accessible nationwide, advising on best accessibility practices in stations, in boarding, and the interior of its new Acela line of trains.

In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

- Advise policymakers on the need to include people with disabilities in clinical trials.
- Advise policymakers on the barriers imposed on people with disabilities because of income and asset limitations in federal program and benefits eligibility requirements.
- Advise policymakers on specific tax exemptions that prevent people with disabilities from attaining employment for federal employment tax purposes.
- Advise policymakers on the rapidly advancing field of fetal medicine and genetic technology and the implications for people with disabilities.

GOAL 3 OBJECTIVES, STRATEGIC RESULTS and PLANNED ACTIVITIES

GOAL 3: Engage policymakers of both the Administration and Congress and respond to their requests for assistance accurately and efficiently.

- 1. Provide timely disability policy briefings for members of the Administration and Hill staff.
- 2. Provide timely written briefing materials to congressional leadership and members of the Administration on policy priorities of the disability community.
- Increase the time NCD staff and appointed Council members dedicate to direct engagement of congressional and Administration policymakers with NCD's policy advice.

In Fiscal Year 2022, we responded to congressional requests for policy assistance; met with and offered briefings to congressional and committee offices regarding our newly released policy research; engaged with congressional and agency offices regarding their own priority areas that have implications for Americans with disabilities; and engaged media on topics on which we have completed research and advised policymakers.

In furtherance of Goal 3, the Council accomplished the following in FY 2022:

- Advised House and Senate offices about the need to expand federal benefits programs to residents in Puerto Rico and the impact of these changes on residents with disabilities. NCD discussed the findings and recommendations from its report, *Disparate Treatment of Puerto Rico Residents with Disabilities in Federal Programs and Benefits*. NCD is currently seeking to schedule a collaborative educational briefing with Puerto Rico's Financial Oversight Management Board, an independent advisory entity within Puerto Rico's government and was created under the Puerto Rico Oversight, Management, and Economic Stability Act or PROMESA (Public Law No: 114-187) to assist with Puerto Rico's fiscal reform and is required to give yearly updates to Congress. NCD is serving on a White House interagency group at economic resilience in Puerto Rico with the hopes of assisting other agencies in ensuring that their own responses are inclusive of the concerns of people with disabilities on the island.
- Advised and assisted the Senate Budget Committee in drafting drug price negotiation language that was included in the Inflation Reduction Act (Public Law 117-169) and

consistent with NCD's <u>QALYs Report</u>. The provision prohibits the Secretary of Health and Human Services from using evidence or findings from comparative clinical effectiveness research in a manner that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill.

- Advised a coalition of U.S. Senators with technical language to use in <u>a letter</u> requesting the Government Accountability Office (GAO) to study the barriers that Americans with disabilities experience in accessing health care. NCD made specific recommendations to ensure that the request did not seek a federal study to substantiate the broad existing body of research on disparities.
- Advised staff from the House Education and Labor Committee regarding an amendment to the National Defense Authorization Act intended to freeze the AbilityOne Commission's rulemaking authority. NCD made staff aware that if enacted, this amendment would freeze AbilityOne's rulemaking process at the time that would end the use of 14(c) certificates that allow employees with disabilities to be paid subminimum wages.
- Advised a Senate office regarding the Fair Housing Improvement Act of 2022 intended to protect veterans and low-income families from housing discrimination and informed the office that NCD references the legislation in its upcoming HCBS report.
- Advised House Energy and Commerce minority staff regarding their request for information related to the minority leadership's disability policy goals for the 118th Congress during their drafting phase. This document has been disseminated to national disability advocacy groups for responses and includes many of NCD's recommendations.
- Regularly met with House and Senate committee staff and leadership staff on a bipartisan basis to discuss how NCD's recommendations can assist in their policy objectives to remove barriers for people with disabilities.
- Held a virtual policy briefing on NCD's <u>Health Equity Framework</u> to approximately 600 participants including congressional, committee, and leadership staff; staff from across HHS; and community advocates.

- Held a virtual roundtable discussion on the need for Medicare coverage for power seat elevation and power standing systems in Group 3 complex rehab technology (CRT) to examine the current barriers that people with mobility disabilities experience when they cannot access this technology. The discussion was well-attended with over three hundred attendees. The information NCD collected from disability advocates was intended to inform policymakers about the need for Medicare coverage of CRTs.
- Presented at a HHS Health Disparities Council monthly meeting on NCD's <u>Health</u> <u>Equity Framework</u>.
- NCD presented at a US Access Board webinar on health equity of approximately 500 attendees. NCD presented on our <u>Enforceable Accessible Medical Standards</u> report.
- Provided briefings on NCD's <u>Health Equity Framework</u> at different times to leadership in the Health Resources and Services Administration (HRSA); National Institute on Disability, Independent Living, and Rehabilitation; the Administration for Community Living; and the Centers for Medicare and Medicaid Services.
- Assisted Congressman Langevin's office relaunch the House Bipartisan Disabilities Caucus with two new co-chairs and a proposed series of policy briefings for the new fiscal year.
- Media engagement NCD's work is routinely highlighted in national media and industry publications, and we regularly receive media inquiries for comment and information on current policies and events related to people with disabilities and to our most recent report releases. A small sampling of our media mentions in Fiscal Year 2022 include the following:
 - Washington Post feature story on experiences with FEMA referenced NCD's report on institutionalization after natural disasters;
 - USAToday, MSN, Disability Scoop, Yahoo News, Clarion Ledger and others covered NCD's 2021 Progress Report on the impact of COVID-19 on people with disabilities;
 - Disability Scoop and Federal News Network covered AbilityOne's announcement of ending subminimum wage employment and highlighted NCD's Page 22 of 52

report on the program that made recommendations for ending the support of Section 14(c) of the Fair Labor Standards Act;

- ABC News referenced NCD's 2017 progress report on poverty and disability, covering workplace accessibility and its impact on employment for people with disabilities.
- Coverage from the NY Times, PBS, Boston Globe, Hartford Courant, Federal News Network on health equity;
- Kaiser Health News covered NCD's report recommendations regarding organ transplant discrimination experienced by people with disabilities;
- The Hill covered NCD's QALY report;
- NPR, PBS, Forbes, BuzzFeed News, The Progressive and others covered NCD's reports on Guardianship and the 'school-to-guardianship pipeline;'
- Several dental publications covered NCD's report on Medicaid coverage of dental care for people with disabilities and its benefits;
- United Nations International Day of Persons with Disabilities included Chairman Gallegos participating in the United Nations World Expo in Dubai UAE broadcast on December 3, 2021. Other participants included former Sen. Tom Harkin, former Rep. Tony Coehlo, and new U.S. Special Advisor on International Disability Rights Sara Minkara (all virtual).

• In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

- NCD will focus on continuing to provide briefings on its health equity framework for congressional staff in committees of jurisdiction, individual congressional offices indicating interest, and federal agencies with responsibility over areas identified in the framework.
- NCD will provide policy briefings to congressional, committee, and leadership staff on new report releases anticipated for FY23, including QALY alternatives, congregate care setting transitions to HCBS, Medicaid oral health care policy,

and misclassification of employees with disabilities by community service providers / sheltered workshops.

 NCD will continue responding to requests for specific subject matter briefings and technical assistance and research for bill text development, convening stakeholders, and responding to constituent inquiries from individual, committee, and leadership offices as well as from colleagues from within the administration.

GOAL 4 OBJECTIVES, STRATEGIC RESULTS and PLANNED ACTIVITIES

GOAL 4: Gather information from subject matter experts and members of the disability community both of Washington, DC, and nationally, to help inform policymakers' work.

- 1. Engage the disability community beyond Washington, DC and solicit their views regarding timely policy matters including but not limited to issues of healthcare equity, employment, and the inclusion of traditionally underserved communities.
- 2. Deliberate and purposeful outreach to disability communities within tribal communities.
- 3. Deliberate and purposeful outreach to disability communities in United States' territories.
- 4. Deliberate and purposeful outreach to the community of disabled veterans.
- 5. Provide opportunities for the disability community to provide input to policymakers on disabilities issues prior to policy decision-making.
- 6. Develop information gathering partnerships to generate effective intelligence for policymakers to use in weighing issues.

In Fiscal Year 2022, in service of its policy development cycle, NCD staff and Council members continued outreach efforts to national organizations, individual constituents, academics, disability coalitions; and disability conferences, all of which informed the research projects as well as helped steer the direction of policy priorities the Council set for the next fiscal year. For every one of our reports released throughout Fiscal Year 2022, our research involved engagement of people with disabilities from across the country in the form of focus groups, interviews, and advisory councils. In each report, we highlighted and

summarized those interactions to elevate first-hand experiences of people with disabilities to the attention of policymakers.

In Fiscal Year 2022, we entered into cooperative agreements with subject matter experts to assist with nearly all our research endeavors to ensure that the information provided to policymakers was current, relevant, and accurate. These agreements are at times with organizations that have specialized expertise in certain policy areas, and at other times with academic institutions or research groups.

In furtherance of Goal 4, the Council accomplished the following in FY 2022:

- Disability community nonprofit meetings NCD continued to meet with staff and leadership of numerous disability nonprofits in FY22 to discuss their organizational policy priorities and ensure that their constituencies' concerns are considered and reflected in the work of the Council. As the result of several such meetings, NCD updated its previously released health equity framework with substantive additions to its recommendations to policymakers, and commissioned a <u>research brief</u> into the impact of the Supreme Court *Cummings* decision on civil rights enforcement for people with disabilities. Several of those meetings included:
 - Met with and later received formal presentations from the Medical Students with Disabilities and Chronic Illness to discuss its efforts to encourage the Liaison Committee on Medical Education (LCME) to revise its standards to require disability competency training of all medical students, as NCD recommended.
 - Met with and later received formal presentations from the Disability Rights Bar and the National Disability Rights Network regarding concerns about the Supreme Court's decision in *Cummings* and the impact on people with disabilities who experience discrimination in health care.
 - Hosted a listening roundtable with leaders from the Deaf and hard of hearing communities regarding concerns and priorities vis-à-vis health equity.
 - Met with leaders from the blind community about concerns and priorities vis-àvis health equity.

- Met with leaders from the Developmental Disabilities, Autism and Family Support Task Force of the Consortium for Citizens with Disabilities regarding medically underserved population designation as well as health disparities designation and corresponding legislation.
- Met with the DD Nurses Association regarding health equity concerns and priorities.
- Received a full-length presentation from leaders in the electromagnetic and chemical sensitivity community in connection to a quarterly Council meeting.
- Met with physicians from Stanford medical school regarding their interest in educating medical providers in the U.S. and internationally on the importance of having accessible medical equipment and on NCD's Health Equity Framework.
- Met with disability community leaders from Boston, MA, Providence, RI, and surrounding areas in anticipation of NCD's in-person quarterly meeting in Providence, RI, set for October 2022, which will feature prominent focus on regional concerns of the community.
- Met with representatives from Mobius Mobility to discuss their concerns about CMS' position that standing and seated systems on power wheelchairs are not medically necessary and therefore are not a covered item under Medicare.

• Other engagements –

- Met with delegation of government officials from Puerto Rico regarding NCD's
 <u>Disparate Treatment of Puerto Rican Residents in Federal Programs</u> report.
- Met with international delegations from Kyrgyzstan, Korea, and Bulgaria on the ADA, IDEA, and the CRPD. Thus far, in FY23 met with delegations from Argentina and Mongolia.
- Met with the Joint Commission (on hospital accreditation) concerning disability competency training of medical professionals and provided them with related recommendations concerning health equity for people with disabilities.

- Disability and other conferences
 - Presented on our <u>Medicaid Oral Health Coverage for Adults with Intellectual and</u> <u>Developmental Disabilities</u> and <u>Disparate Treatment of Puerto Rican Residents</u> <u>in Federal Programs</u> report at the ANCOR national conference in Miami, Florida.
 - Presented on our <u>Health Equity Framework</u> at the National Association of Councils on Developmental Disabilities (NACDD) Future of Health Care 2022 conference in Washington, DC, to several hundred individuals.
 - Presented at the Jacobus tenBroek Disability Law Symposium on our <u>Progress</u> <u>Report: The Impact of COVID-19 on People with Disabilities</u> report and on our <u>Health Equity Framework</u>.
 - Participated and presented at the Prenatal Disability Education Summit at Johns Hopkins Medical Campus on NCD's health equity and related work.
 - Presented at United Cerebral Palsy's Conference on Latinos with Disabilities.
 - Presented at Melwood's "Inclusion through Policy Innovation" conference.
 - Chairman Gallegos joined American Council of the Blind's podcast as a featured guest.
 - Presented virtually at the World Expo, Dubai for the United Nations International Day for Persons with Disabilities.
 - Presented a workshop titled "Optimizing Care Systems for People with Intellectual and Developmental Disabilities" at the National Academies of Sciences, Engineering, and Medicine
 - Spoke at the Partnership to Improve Patient Care's 2021 Forum regarding NCD's advice to policymakers to expressly prohibit use of the QALY.
 - Presented at the American Council of the Blind's leadership conference.
 - Presented on NCD's body of work regarding improving dental health of people with IDD at the AHEAD Symposium "Universal Dental Curriculum."

- Presented on NCD's <u>Enforceable Accessible Medical Standards</u> report at Stanford University's Disability in Healthcare and Medicine conference.
- Presented on NCD's employment recommendations at the Society of Human Resource Management's policy conference.
- Opportunities for public input NCD continues to engage opportunities for the Council to hear directly from members of the public; meet regularly with international delegations when requested; and provide regular disability policy briefings for members of the Administration and congressional staff. We continually receive public comment via all social media platforms our website as well as to our designated public comment email account. In FY22, NCD collected 224 public comments via email across six live events. This figure is not inclusive of comments posted in the chat on virtual events NCD has held.
- Developed new agency website and listserv NCD in FY22 worked with General Service Administration Technology Transformation Services (TTS) web developers on a complete structural overhaul of our antiquated NCD.gov website by creating and fielding a new beta.ncd.gov official government website on the Federalist Cloud.gov platform. The beta site will become the primary website in early FY23 upon completion of content migration that will improve security and accessibility. We developed a new email listserv protocol to facilitate regular communication with advisees and the general public regarding our activities and policy recommendations and enhance accessibility and ease of use.
- Deliberate and purposeful outreach to people with disabilities in tribal communities NCD entered into a Memorandum of Understanding with National Indian Coalition on Aging (NICOA) to update NCD's 2003 American Indian and Alaskan Native Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide. NICOA is ushering the report through the editing process with a hopeful release and coordinated dissemination process in the first quarter of fiscal year 2023. In addition, NCD identified stakeholders from American Indian and Alaska Native communities to consult with tribal officials in the development of federal policies that have tribal implications.

- Deliberate and purposeful outreach to people with disabilities in U.S. territories NCD released a report titled <u>Disparate Treatment of Puerto Rican Residents in Federal</u> <u>Programs</u>, in May 2022, that highlights the disparities between federal programs offered to U.S. citizens with disabilities living on the mainland versus those living in Puerto Rico. Unrelatedly, NCD staff began outreach to disability leaders in Guam, American Samoa, the Northern Mariana Islands, and the U.S. Virgin Islands, in anticipation of future virtual town halls with the disability communities there. In FY24, will also kick off a series of reports on disability and tribal lands and disability in US territories.
- NCD continued to host virtual quarterly Council meetings with increased public participation. Due to the virtual environment, NCD's quarterly Council meetings featured state disability policy highlights without incurring expenses associated with invited speaker travel. The virtual meetings were attended by gradually increasing numbers of people across the country, and topically targeted public comment periods helped provide valuable information for NCD's ongoing research endeavors.
- NCD hosted a health equity stakeholder call with nearly 600 attendees. The virtual Zoom webinar attracted over 1,000 registrants who were interested in learning more about NCD's <u>Health Equity Framework</u>. NCD edited the recorded webinar and remediated it for accessibility, posting it online for additional views.
- Addition of language in cooperative agreements Last year, in response to Executive Order 13985, "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," NCD amended its cooperative agreement requirements language, which had read "NCD wants to ensure there is stakeholder involvement in Page 42 of 68 the findings and recommendations. The inclusion of people with disabilities must be integral to the planning, development, and execution of this project. At least one section of the report should focus on stakeholder input, but input should be integrated throughout," to further add, "NCD wants to ensure there is stakeholder involvement in the findings and recommendations. The inclusion of people with disabilities, including people with disabilities who are multiply marginalized (black, indigenous, people of color, LGBTQ, e.g.), must be integral to the planning, development, and execution of this project. At least one section of the report should focus on stakeholder input, but input should be integrated throughout." This language

was integrated into the cooperative agreements we relied upon to generate the reports we are now concluding and readying for release in the fall, which reflect advice to policymakers that is inclusive of the breadth of diversity of the disability community constituency.

In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

- NCD will continue to utilize listening sessions and stakeholder engagements in its research that draws upon expertise and perspectives from diverse cross-sections of the community.
- NCD will continue to host town hall style listening sessions with members of the disability community from areas to which the Council travels, as well as target the U.S. territories (Guam, American Samoa, North Mariana Islands, and the U.S. Virgin Islands).
- NCD will finalize and release its updated Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide.

GOAL 5 OBJECTIVES, STRATEGIC RESULTS and PLANNED ACTIVITIES

GOAL 5: Enhance agency operational and programmatic internal controls to effectively service execution of statutory duties.

- 1. Enhance planning and evaluation of all agency projects to ensure continual improvements.
- 2. Ensure compliance with financial regulatory and reporting requirements.
- 3. Regularly evaluate and as needed update internal policies and procedures to ensure federal compliance, improved efficiencies, and internal controls.

In furtherance of Goal 5, the Council accomplished the following in FY 2022:

- The Council continues to work collaboratively with the Department of Homeland Security to implement mandated cybersecurity requirements. We have complied with all mandated requirements to the maximum extent that our budget has allowed.
- National Archives and Records Administration (NARA), Management Federal Records Modernization Initiative (FERMI) The M-19-21 directive issued by NARA requires federal agencies to transition to electronic documents by December 31, 2022. This includes legacy content. After this time, NARA will no longer accept permanent or temporary records from agencies in non-electronic format. We have been working diligently to meet this deadline by implementing functions in the SharePoint platform and moving exclusively to cloud storage. This government-wide initiative has allowed the agency to transfer our paper documents to the Federal Records Center, designate a Senior Agency Official and Agency Records Officer for records management which include training, scheduling records, workflows, and retention periods. The ongoing process for digitization will require maximum staff resources. M-19-21 contextualizes our commitment to digital government and helps explain the progress our agency has made in managing records electronically for full compliance by the December 2022 deadline.
- Plan of Action and Milestones (POAMs) The Council continued to work across fiscal years to ensure our IT infrastructure was secure and we were moving toward compliance with all regulatory requirements.
- SharePoint The Council continued its SharePoint platform development to support the transition to electronic documents by NARA's deadline of December 31, 2022.
- Updates to EEOC Policies and Procedures Pursuant to 29 C.F.R. § 1614.102(e), NCD continued to outreach to Equal Employment Opportunity Commission (EEOC) for technical assistance to ensure our policies are in compliance with all mandates and requirements.
- Updates to Administrative and Financial Policies and Procedures NCD continually monitors and updates our internal policies and procedures in response to agency needs, improving internal controls and in response to government wide directives.

- Equipment Donation The Council's computer equipment was fully depreciated in FY 2022. This provided NCD the opportunity to repurpose and donate in accordance with federal guidelines.
- In FY 2022, we promoted an environment that ensured our operations include multilevels of internal controls. We ensured all operation components were safeguarded against waste, fraud, and abuse, which included advising and bringing areas of concern to agency leadership to ensure compliance and oversight.
- NCD evaluated the agency's operations during a national pandemic. This required a thorough analysis of ever-changing guidance and directives. As a small independent agency, we did an outstanding job monitoring, and implementing changes to guidance and directives received during the pandemic.
- NCD worked with GSA to initiate an Interagency EIS Transition for services.
- NCD reviewed and updated our travel procedure to maximize oversight and to ensure NCD official travel procedures were in compliance with all applicable federal travel regulations and complied with the ever-changing COVID-19 pandemic or other public health guidance. This change was followed by a training presentation for Council members and staff.
- NCD issued a request for proposal (RFP) for cyber security support with implementation occurring in the FY 2022 and throughout FY 2023. This agreement will assist the agency to ensure compliance with all cybersecurity requirements; identifying and assessing significant risks related to information security; and safeguarding of information system assets by identifying and presenting solutions to solve potential and actual security problems.

In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

 Plan of Action and Milestones (POAMs) - The Council will continue to work across fiscal years to ensure our IT infrastructure is secure and we were moving toward continued compliance with all regulatory requirements.

- Updates to Administrative and Financial Policies and Procedures NCD will continue to monitor and update our internal policies and procedures in response to agency needs, improving internal controls and in response to government wide directives.
- SharePoint The Council will continue to develop the SharePoint platform. In FY 2023, we will incorporate workflows to improve internal operations and assist in continuity and process.
- Financial Audit The Accountability for Tax Dollars Act requirement for an annual preparation and audit of financial statements of smaller agencies was exempted by OMB in recognition of our stewardship. This continues to result in a biennial cost savings for the Council. The Council will incur the cost of completing an audit for Fiscal Year 2022 and Fiscal Year 2023 in Fiscal Year 2023.
- NCD will continue to work with EEOC to receive technical assistance and update and ensure compliance with all federal EEO regulations.
- We will continue to promote an environment that ensures our operations include multilevels of internal controls, and our operational components are safeguarded against waste, fraud, and abuse.
- NCD will continue to evaluate the agency's operations following the national pandemic. We will continue to analyze guidance and directives and implement changes in response to our analysis.
- As NCD begins to travel to host public meetings, we will continue to review and updated our travel procedure to maximize oversight and to ensure NCD official travel procedures are in compliance with all applicable federal travel regulations and comply with all public health guidance.
- We will monitor and implement processes as identified through the cyber security support agreement. This agreement will continue to assist the agency in complying with all cybersecurity requirements; identifying and assessing significant risks related to information security; and safeguarding of information system assets by identifying and presenting solutions to solve potential and actual security problems.

• We will begin the process of transitioning financial services vendors in an effort to secure improved service and internal controls.

GOAL 6

OBJECTIVES, STRATEGIC RESULTS and PLANNED ACTIVITIES

GOAL 6: Recruit, retain, and develop a highly qualified professional staff in order to effectively service execution of statutory duties.

- 1. Engage in a human capital management assessment to evaluate staffing and consider opportunities for workforce optimization.
- 2. Enhance new staff, members, and intern orientation materials and process.
- Encourage staff to conduct SWOT (strengths, weaknesses, opportunities, and threats) analyses as a means of identifying professional development opportunities and enhancing performance.

In furtherance of Goal 6, the Council accomplished the following in FY 2022:

- We experienced the turnover of one council member and swore in a new member in late August 2022. We continue to improve and enhance the onboarding process for staff, members, and interns.
- DEIA Strategic Plan NCD submitted the DEIA strategic plan as required of federal agencies. NCD saw this as an opportunity to further embrace and enhance diverse, equitable, inclusive and accessible employment opportunities. NCD incorporated DEIA in all aspects of our operations, including updating our cooperative agreement language, ensuring that all our research endeavors also reflect our commitment to DEIA principles.
- Flexible Work Program NCD piloted and later finalized implementation of a remote work option as a workplace flexibility that benefits work-life balance for NCD's hardworking employees as well as optimizes NCD's options for future hires.

- Intern Program In FY 2022 NCD began development of an intern program which incorporates DEIA initiatives. NCD provided intern opportunities to 4 graduate students in FY 2022.
- NCD management revised the performance evaluation period to ensure management and staff had greater opportunity for adequate review and discussion and to add greater distance between the final assessments and the fiscal year closeout.
- NCD participated in the Federal Employee Viewpoint Survey (FEVS), and continually encouraged participation by provided ongoing updates and reminders to management and employees. Agency management worked collaboratively to ensure the agency specific questions would provide helpful data to the management team.
- NCD management committed to increase participation in leadership training and began acting on that commitment through group management trainings.

In Fiscal Year 2023, NCD will prioritize work in the following areas of focus:

- NCD will continue to assess ways in which it can support its staff during the first full year of its flexible work policies, including maximum telework and remote work, gliding flex, and compressed work schedules, including assessing technology needs and updating administrative policies as necessary.
- NCD will finalize its internship program, incorporating DEIA principles in outreach and recruitment, and will regularly assess the program for opportunities for improvement. We have thus far hired 2 interns and a doctoral practicum student this fiscal year.
- DEIA Strategic Plan –NCD will continue in its long tradition of promoting diversity, equality, inclusion, and accessibility in all aspects of our operations, performance discussions, and workforce optimization decisions. In January 2023, NCD presented on incorporating accessibility into operations at OPM's DEIA Summit.
CROSS-AGENCY COLLABORATIONS

NCD's policy advisement is often directed at other federal agencies, and it is vital that we maintain open communication and relationships with agencies across the government in furtherance of our research to policymakers and to also help close key feedback loops for agencies, by assisting them in hearing from people with disabilities across the country. Fostering such cross-agency relationships supports our strategic objective to develop policy recommendations and encourage collaboration. With each policy project, we share our recommendations in advance with the agencies we are examining to ensure technical accuracy and strives to follow up with the same agencies in assessing their implementation of our recommendations. The Council regularly engages with many other federal agencies. Please note the many cross-agency collaborations we have previously highlighted in Goal 3. In addition to those, many others include:

- Government Accountability Office NCD met with GAO to discuss the US Access Board, its mission, its cross-agency collaborations, and its operational efficiencies in relation to a GAO study on the US Access Board.
- Administration on Community Living NCD holds monthly standing calls with leadership from ACL to update one another on agency work and near-horizon projects.
- **US Access Board** NCD holds monthly standing calls with leadership from the US Access Board to update one another on agency work and near-horizon projects.
- Domestic Policy Council (DPC) Interagency Workgroup on Disability NCD joins the Domestic Policy Interagency Workgroup on Disability and its related subcommittees regarding a range of issues identified as agenda items by the Director of Disability Policy at the DPC.
- Small Agency Council (SAC) Executive Committee, Partnership with General Services Administration (GSA) Work Group – NCD staff are members of the SAC Executive Committee which is charged with reviewing and providing advisement on activities within GSA's Office of Administrative Services and Human Resources Line of Business, Office of Customer & Stakeholder Engagement. Office

of Analytics, Performance & Improvement and GSA's Management Through COVID-19.

- The Small Agency Chief Information Officer Council (SACC) and Small / Micro-Agency Chief Information Security Officers Council (SMAC) – NCD participates in the SACC and SMAC and leveraged the expertise of the forum in relation to our drafting of a cybersecurity RFP.
- Interagency Group Meeting on Javits-Wagner-O'Day Act Amendments NCD participated in a listening capacity during a several months' long series of interagency meetings hosted by the Ability One Commission in relation to recommendations of the Section 898 Panel.
- Department of Treasury NCD is in communication with Treasury staff to discuss provisions of the tax code that are inconsistent with current disability policy and prevents people with disabilities from attaining employment status when they choose to work in sheltered workshops.

NATIONAL COUNCIL ON DISABILITY BUDGET Cost Discussion (Appendix A)

	FY2023	
	Appropriated	FY2024 Budget
DESCRIPTION	Budget	Request
BUDGET TOTAL	3,850,000	4,000,000
PERSONNEL	2,186,522	2,241,046
TRAVEL	75,000	140,000
RENT, UTILITIES AND	301,620	307,500
COMMUNICATIONS	301,020	307,300
PROGRAM, RESEARCH AND	258,800	355,500
PRINTING	200,000	333,300
TRAINING AND PROFESSIONAL	20,000	27,500
ASSOCIATIONS	20,000	27,300
AUDIT	42,500	0
PAYROLL, ACCOUNTING AND HR	509,000	215,000
SERVICES	000,000	210,000
SUPPORT CONTRACT SERVICES	191,800	249,604
INFORMATION TECHNOLOGY	98,000	285,500
PAYMENTS TO FEDERAL AGENCIES	1,776	4,750
SUPPLIES, SUBSCRIPTIONS AND MATERIALS	63,482	66,100
SOFTWARE & EQUIPMENT	63,000	67,500
ANTI-DEFICIENCY	38,500	40,000

APPENDIX A

Cost Discussion

NCD is committed to fulfil its mission of advising the President, Congress, and other federal agencies regarding federal policies' impact on people with disabilities in a cost-effective manner.

- The Council presents a budget of \$4,000,000 for Fiscal Year 2024.
- The Council's appropriated budget for Fiscal Year 2023 is \$3,850,000.

In Fiscal Year 2024, NCD remains committed to delivering mission critical outcomes while streamlining our operational expenses wherever possible as a means of optimizing our appropriation toward expenses directly connected to research and advice activities. In so doing, NCD judiciously utilizes taxpayer dollars in support of the national priority to reduce deficits.

APPENDIX B

Analysis of Resources

PERSONNEL

FY 2023 \$2,186,522

- FY 2024 \$2,241,046
 - Our Fiscal Year 2023 budget supports 9 Council members and 11 staff (FTEs), and includes mandated salary increase established to be a 4.6%, as well as a not-toexceed (NTE) hire to join the Administration, Finance, and Operations team.
 - Our Fiscal Year 2024 budget supports 9 Council members and 11 staff (FTEs), one NTE hire, and regularly scheduled performance increases per OPM policy and associated benefits. The increase in FTEs is in support of the mission critical work of the agency.

Recruiting and retaining full-time federal employees is critical to fulfillment of the Council's mission.

TRAINING AND PROFESSIONAL ASSOCIATIONS

FY 2023 \$ 20,000

FY 2024 \$ 2,500

- In support of Strategic Goal 6, to recruit, retain, and develop a highly qualified professional staff in order to effectively service execution of statutory duties, NCD is committed to setting aside training dollars and memberships in professional organizations for all employees.
- All employees are encouraged to utilize training dollars in support of their professional development and the agency's mission. Accordingly, we endeavor to invest funding to train, advance, and retain the existing workforce.

TRAVEL

FY 2023 \$75,000

FY 2024 \$140,000

- For Fiscal Year 2023, in anticipation of ongoing travel restrictions as a result of COVID-19, and budget restraints NCD reduced the travel budget to support one inperson Council meetings and preparatory activities and visits
- For Fiscal Year 2024, NCD budgeted for two in-person Council meetings and preparatory activities and visits.

The largest portion of the Council's travel budget is devoted to the cost of fulfilling our statutory requirement to conduct public meetings no less than four times each year.

Additionally, in conjunction with policy development or engagement activities, at times, the Council convenes policy forums to gather or provide expert information. On these occasions, we may extend invitations to subject matter experts. This invitation may include travel related costs.

All travel is processed in accordance with federal per diem regulations.

RENT, UTILITIES AND COMMUNICATIONS

FY 2023\$301,620FY 2024\$307,500

We renewed our lease with the General Services Administration pre-pandemic, effective October 1, 2021, for 15 years through September 30, 2031. We negotiated a reduced cost by entering a 15-year agreement. The ability to remain at the current location, which is accessible for people with disabilities by three major Metro rail lines and Metro bus was the primary motivation for renewing the existing lease.

With the majority of staff being people with disabilities, and as the federal voice to policymakers of the over 61 million Americans with a wide variety of disabilities, we also

utilize several communication methods to facilitate the work of members and staff, as well as to engage with stakeholders.

Initially in response to the pandemic, and later because of the success of the experience, NCD embraced remote work opportunities, and made them available for all employees. NCD management continues to monitor the success of flexible work opportunities in anticipation of future savings related to rent and has begun planning discussions with the General Services Administration regarding reducing the agency's real estate footprint in future fiscal years.

PROGRAM, RESEARCH AND PRINTING

FY 2023\$258,800FY 2024\$355,500

- For FY 2023, our budget will support policy projects related to fulfilling the mission of the Council, including our annual progress report. In the remainder of FY 2023, we will pursue additional research regarding how tax policy is impacting people with disabilities – specifically worker misclassifications in sheltered workshop environment; as well as a report focusing on the inclusion of people with disabilities in clinical trials.
- For FY 2024, our budget will support policy projects related to fulfilling the mission of the Council, including our annual progress report. NCD will also commence research and report on the experience of people with disabilities on tribal lands; and fulsome research and report on barriers that people with mobility disabilities confront in public rights of way, federally-funded fitness and recreational facilities, and airline travel.

AUDIT

FY 2023 \$42,500 FY 2024 \$0

As part of our reform plan and allowed per the Accountability for Tax Dollars Act requirement for an annual preparation and audit of financial statements of smaller agencies, we are exempted by the office of Management and Budget (OMB) for an annual audit in recognition of the stewardship we have presented through ongoing unqualified audits.

The audit for FY 2022 and FY 2023 will occur in Fiscal Year 2023 with Fiscal Year 2023 funds at an estimated obligation of \$42,500 for an independent audit of NCD's financials. The audit reviews the Council's internal control over financial reporting in compliance with OMB audit guidance for expressing an opinion on financial statements.

PAYROLL, ACCOUNTING AND HR SERVICES

FY 2023\$509,000FY 2024\$215,000

- For FY 2023, our budget increased by 140% to support the fees associated with an anticipated transition in service providers to better meet the needs of the agency.
- For FY 2024, our budget will go back to the normal fee to support the payroll and accounting services for the agency.

We contract with the General Services Administration (GSA) Commissions and Boards (CABS) human resource services and Office of the Chief Financial Officer (OCFO) for payroll, accounting, and HR services. Through these interagency agreements, we receive support to complete payroll, accounting, and human resource services. Our agreements position NCD to utilize ad hoc services such as legal consultation, human relations support, and other services as identified. We do not have the resources to employ full-time staff with expertise in all areas the agency requires. With oversight and support of professional FTEs, these service level agreements facilitate smooth operations and assists in fulfilling federal requirements.

SUPPORT CONTRACT SERVICES

FY 2023\$191,800FY 2024\$249,604

- For FY 2023, our contractual services budget supports the operational needs of the agency, and reasonable accommodations for staff, members, and invited guests.
- For FY 2024, our contractual services budget supports the operational needs of the agency and reasonable accommodations for staff, Council members, and invited guests.

Many of the staff and Council members are people with a variety of disabilities. We provide accommodations for employees with disabilities during working hours and at meetings and events. In FY 2024, our increase in budget for contractual services reflects an increase in accommodation supports.

INFORMATION TECHNOLOGY (IT) AND SOFTWARE AND EQUIPMENT

FY 2023 \$ 98,000

FY 2024 \$ 285,500

- For FY 2023, I funding is necessary for NCD to move toward full and ongoing compliance with IT and cybersecurity mandates. In Fiscal Year 2023, we will roll out necessary software to ensure compliance and focus on implementing the following mandates:
 - Manage NCD's risk management framework for security compliance using OpenFISMA+. The risk management framework describes how an agency must access, monitor, and respond to risk;
 - Upload and monitor our agency Plans of Actions and Milestones (POAM's), review and respond to the risk of classified and low, medium, or high and guide the agency toward compliance;
 - Support and upkeep on SharePoint;
 - Communicate on secured phone lines that are IP based;
 - Provide ongoing security for the agency by maintaining MTIPS to address high level federal requirements with a secure connection to the public internet in full compliance with OMB's Trusted Internet Connection (TIC); and
 - Employ or contract with a Cyber Security Specialist to write policies, procedures, and standards following OMB & DHS Directives in addition to providing ongoing support and compliance with cybersecurity mandates.

 For FY 2024, NCD will continue to move toward full and ongoing compliance with IT and cybersecurity mandates. We will also have a full year of service with new Cyber Security Vendor.

As a small agency, we secure outside support to assist in meeting the Council's IT and cybersecurity requirements. Related expenses continue to represent a significant amount of the Council's appropriation. Additional expenses are a result of new and ongoing federal requirements such as the EINSTEIN cybersecurity initiative, and implementation of TIC 3.0 and OpenFISMA++, to name a few. These costs are ongoing to ensure compliance with all cybersecurity and FISMA mandates, and to assist in the security and protection of all Government networks.

PAYMENTS TO FEDERAL AGENCIES

FY 2023\$ 1,776FY 2024\$ 4,750

Costs are relative to the anticipated needs of the Council during each fiscal year in addition to the Council's decision to utilize fee-for-service expertise.

As a small agency, we secure services through interagency agreements with other federal agencies for technical functions such as job postings, procurements, and security services, to name a few. Under the oversight of professional staff, utilizing interagency agreements in this way assists us in fulfilling federal requirements by providing subject matter expertise.

SUPPLIES, SUBSCRIPTIONS AND MATERIALS

FY 2023\$ 63,482FY 2024\$ 66,100

Costs are relative to the anticipated needs of the Council during each fiscal year.

The Council utilizes professional periodicals, subscriptions, technical publications, and services to stay informed of policy developments, conduct legal and other research, and

access federal directories in furtherance of its mission. These resources are essential in assisting staff to fulfill mission critical work for the Council.

As a micro agency, NCD is a good steward of federal funds and utilizes a very small budget for office supplies, furniture and general supplies each year. In FY 2023, we anticipate the costs of supplies to modestly increase as we support our employees in flexible telework environments. However, furniture needs are expected to decrease due to the success of our remote work program for a net zero change.

ANTI-DEFICIENCY

FY 2023	\$ 38,500
FY 2023	\$ 40,000

The Council reserves one percent of our annual appropriated budget for unanticipated expenses and to ensure the Council does not exceed available funds.

APPENDIX C

Organizational Chart



APPENDIX D

MAJOR MANAGEMENT PRIORITIES AND CHALLENGES

Costs of Implementing Federal Cybersecurity Requirements

We continue to enhance our cybersecurity program. NCD continues to benefit from our Memorandum of Agreement (MOA) with the Department of Homeland Security (DHS) and the Department of Defense (DOD). NCD is committed to deploy cybersecurity strategies that will secure America's cyber networks. Our MOA with the DHS, Office of Cybersecurity and Communications ensures the deployment of EINSTEIN Cybersecurity capabilities. We continue to deploy EINSTEIN Intrusion Prevention Security Services (IPSS) on our networks. These services look for network traffic and indicate known or suspected malicious cyber activity. NCD continues to make strides to improve our cybersecurity posture by utilizing initiatives in the Federal Government such as the Continuous Diagnostics and Mitigation (CDM) program Federal Government cybersecurity and Infrastructure Security Agency (CISA).

Activity	FY2	23	Description
			Manages NCD's risk management
			framework for security compliance using
			Cingular. The risk management
			describes how an agency access,
			monitor, and respond to risk. A
			contractor uploads and monitors all of
			our agency plans of actions and
			milestones (POAM's) and informs the
Cingular	\$	6,000.00	agency of the risks.
			MTIPS provides security for agencies
			online traffic and addresses high level
			federal requirements with a secure
Managed Trusted			connection to the public internet in full
Internet Protocol Services			compliance with OMB's Trusted Internet
(MTIPS)	\$	33,332.00	Connection (TIC).
			Authority to operate on Government
ATO (Authority to			network which needs to be updated
Operate)	\$	75,000.00	every 12 months.

In FY 2023, the total budget needed to implement improvements to the efficiency and effectiveness of our operations in the area of cybersecurity is summarized below.

Cyber Security Support	\$ 120,000.00	Cyber Security Contractor(s) to write required policies, procedures, and standard in additional to providing support by following OMB & DHS directives & mandates.
Continuous Diagnostics and Mitigation (CDM)	\$ 6,000.00	CDM is required by DHS. It helps strengthen the cybersecurity of government networks and systems. This tool develops and reports that the agency is CDM compliant and reports to OMB.
		System Security Plan (SSP) will reveal what system(s) are in place and what support is needed. This will also cover penetration testing which is an ethical hacker that connects to your network in an attempt to obtain passwords. Once the test is done, the agency will know
Security Assessment &		what to improve. A risk assessment will
Authorization	\$ 35,000.00	also be completed on our network.
Total Cost	\$ 275,332.00	

MAJOR MANAGEMENT PRIORITIES & CHALLENGES (continued)

Costs of developing a workforce for the 21st Century

Management's major priorities for the National Council on Disability for Fiscal Year 2024 are to:

- 1. Thoughtfully assess agency workforce, workload, and workflow against any applicable executive orders and OMB guidance;
- 2. Pursue ongoing review and updates to our internal control policies and procedures;
- 3. Continue compliance with mandated cybersecurity protocols, as the budget allows; and
- 4. Hire, train, develop, and retain an exceptional workforce, with a priority on hiring a diverse workforce, including people with disabilities.

An enduring management challenge is how best to approach the allocation of the Council's limited financial and human resources. By recognizing the expertise of professional staff, and those staff serving in dual roles since 2018, the Council has been operating with eleven full-time staff and nine Council members. The Council members balance their service to the Council with their own full-time careers. Given the breadth of our mission, the scope of our engagement, policy development, and collaborative activities are often limited by the lack of workforce. Our modest budget and small workforce necessitate balancing and prioritizing stakeholder needs with available resources.

Related to the allocation of resources, maintaining a continuity of workforce is both a management priority and challenge. Unlike a larger agency that can withstand numerous vacancies without immediate implication to mission accomplishment or the operational integrity of the Council, in an agency of our size, even a single vacancy can create a palpable effect on the Council. Additionally, with the extent of discrete responsibilities every federal agency faces, regardless of size, individual employees may be the sole individual responsible for and knowledgeable of how to complete tasks. This necessarily creates risk for which the Council must account for and control. Therefore, continuity of leadership, employee retention, professional development, and cross-training among

employees are always priorities of management as are persisting in efforts to seek opportunities to strengthen and add to the number of staff.

We establish and maintain effective internal control and financial management systems that meet the objective of the Federal Manager's Financial Integrity Act. Based upon the results of the independent auditor's biennial report, we can provide reasonable assurance that our internal control over the effectiveness and efficiency of operations and compliance with applicable laws and regulations is operating effectively and no material weaknesses were found in the design or operation of the internal controls.

NCD publishes several full-length reports every year, in addition to advising and responding to multiple requests on various topics from federal policymakers. Most research projects involve outside contractual assistance. These full-length reports are fulsome research endeavors that entail a broad scope of policy consideration, and/or address an emerging topic or technology that we urge policymakers to consider. While we will continue to fulfill our mandate to serve policymakers and respond to the disability community's interests and publish annual research/policy reports, we are also an agency with operational requirements in addition to ever greater needs in the disability community to fulfill.

STAFFING NEEDS TO SUPPORT THE MISSION OF THE COUNCIL

Since the inception of NCD and its original statutory charge to review and advise on laws and policies impacting people with disabilities, numerous amendments to existing civil rights laws as well as the passage of new laws has vastly expanded the scope of our work, and yet, the workforce of the Council has remained level for many years. However, the number of appointed council members decreased as a result of the Workforce Innovation and Opportunity Act (WIOA). The reduction in appointees also presented a reduction in the amount of professional experts who could bring their respective areas of expertise to bear on behalf of the Council's work.

Given our charge to review and advise on existing and proposed laws and policies and the growing number of laws and policies for people across all types of disabilities, regardless of age or severity of disability, it has become a far more difficult task for the Council to service the mission of the Council with level staffing. To be timely and responsive to our advisees, the workload for existing staff has continually increased, with several staff Page **51** of **52**

completing assignments that equal the workload of multiple positions. Any loss in funding directly impacts the mission critical work of the Council.

Despite our small size, NCD must comply with requirements placed on much greaterresourced agencies. The financial demands of mandated requirements have the potential to compromise NCD's ability to complete the work that is critical to the mission of the Council, the Federal Government, and the disability community. To ensure the safety and security of the government's network, the demand for resources to support the mandated requirements for compliance are ongoing for the foreseeable future.

Any increase in our appropriations for FY 2024 will be used to shore up the workforce needs of the Council related to the mission-critical policy research and advisement work of the Council and continued compliance with cybersecurity requirements. The need is acute, particularly during an ongoing time of focus on the needs of a burgeoning aging population and new scores of people experiencing "long-COVID," who will require multi-disciplinary policy solutions.

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