CCD
CONSORTIUM FOR CONSTITUENTS
WITH DISABILITIES

March 12, 2025

SUBMITTED ELECTRONICALLY

NIH Disability Health Research Coordination Team
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director
National Institutes of Health
Email: disabilityhealthresearch@nih.gov

RE: CCD Health Task Force Co-Chairs Response to Request for Information (RFI): on the Framework for the NIH Strategic Plan for Disability Health Research FY26-FY30 Notice Number: NOT-OD-25-038

The Health Task Force co-chairs of the Consortium for Constituents with Disabilities (CCD) appreciate the opportunity to submit comment as part of the Request for Information (RFI) on the National Institutes of Health (NIH) Strategic Plan for Disability Health Research ("the Strategic Plan").

CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

The Strategic Plan will help ensure that the NIH is conducting and supporting research that is critical to people with disabilities. CCD asks the NIH to continue this work and maintain its commitment to promoting the health and well-being of people with disabilities. The information gathered through the responses to this RFI should guide the refinement of the framework and the development of the strategic plan. CCD also asks the NIH to ensure that people with disabilities, including those representing the full spectrum of disabilities, are involved in the development of the strategic plan. CCD offers its thoughts below on the NIH's prioritization of critical research areas, and would be glad to continue to work with the NIH on this important initiative.

Health Disparities & Barriers to Care

Accessibility

Despite legal protections, people with disabilities continue to face significant barriers in accessing quality healthcare. Many medical offices, diagnostic equipment (e.g., mammography machines, exam tables), devices like MRI machines, weight scales, and blood pressure cuffs are not designed for all bodies. Equipment booking policies require accommodating the communication and scheduling needs of people with disabilities. Telehealth platforms, patient portals, and health apps also frequently exclude people with disabilities. NIH should fund research into developing accessible, universally designed and available medical devices. This research should investigate the ways in which restrictive payer policies can inadvertently impede advances in healthcare applications that work through devices like smart phones that happen to have other non-health uses.

Ableism and Discrimination

People with disabilities often experience discrimination, biases about their quality of life and the value of their life from medical providers, which can affect their access to care.[1] Disabled individuals receive fewer routine screenings (e.g., cancer screenings, vaccines, dental care), leading to worse health outcomes.[2] People with disabilities, particularly those with communication challenges, often have their pain dismissed or undertreated.[3] Some organ transplant programs deprioritize disabled patients.[4] Similarly, disability advocates across the board raised concerns about medical rationing decisions that devalued disabled lives during the COVID-19 pandemic.[5] But even with these few examples, the consequences of health care discrimination on disabled peoples' lives remains understudied NIH should encourage research about how ableism among healthcare providers influences diagnosis, treatment recommendations, and pain management in health and mental health care.[6] NIH should then identify effective interventions to improve routine screenings and vaccinations for disabled populations, develop strategies to reduce ableist bias among medical professionals, and establish best practices for a national health crisis response that prioritizes the health and rights of persons with disabilities. Very little is known about the effects of compound marginalization, such as disparities in access to care for disabled people of color. Revisions to the Health and Human Services (HHS) Section 504 rules under the Rehabilitation Act were intended to address many of the issues around bias, discrimination and lack of accessibility in

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[1] See https://publications.aap.org/pediatrics/article/152/1/e2022060975/192154/Perceived-Disability-Based-Discrimination-in?autologincheck=redirected

[2] See https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-ADA-2017.pdf

[3] https://www.sciencedirect.com/science/article/pii/S1526590013009954

[4] See https://www.ncd.gov/assets/uploads/reports/2019/ncd_organ_transplant_508.pdf

[5] See https://pubmed.ncbi.nlm.nih.gov/32463287/

[6] See https://www.sciencedirect.com/science/article/pii/S2667321524001070#:~:text=Examples%20of%20ableism%20include%20medical,foster%20accessible%2C%20inclusive%20mental%20healthcare.

healthcare. NIH should prioritize investigating whether these updates are being effectively implemented nationwide.[7]

Disability-Inclusive Data Collection & Research Gaps

People with disabilities have been largely absent from mainstream health research.[8] Many public health surveys and medical research studies fail to include demographic disability status, making it difficult to track health disparities. [9] Many clinical trials exclude people with disabilities, leading to a lack of data on how treatments affect them.[10] This has a huge impact on the effectiveness of treatments for people with disabilities. Although NIH collects disability status as part of demographic data for researchers, it is not mandatory to include disability status in all federally funded health research studies. We welcome NIH's recognition of people with disabilities as a population experiencing health disparities,[11] however there needs to be greater and more deliberate inclusion of persons with disabilities in research studies and clinical trials.[12] NIH should therefore mandate the inclusion of disability status in all NIH-funded research and require disability representation in drug trials and medical studies. Additionally, NIH should investigate disparities in pain management for disabled individuals and establish guidelines to ensure equitable treatment.

Artificial Intelligence in Healthcare

The use of artificial intelligence (AI) has pervaded all aspects of healthcare, from clinical decision-making among providers to utilization management among insurers to public-facing documentation and patient service interactions. The use of algorithmic decision-making tools, and foundational concerns about the embedded presence of algorithmic bias, stems in large part from the dearth of transparency about how such tools are trained and how they operate. The lack of disability-inclusive data collection and research leads directly to gaps in how AI tools assess the well-being and treatment potential of people with disabilities and other underserved groups. Healthcare AI that is trained using decades of discriminatory health insurance information that lacks any consistent exposure to the correct application of reasonable accommodation and policy modification in healthcare is likely going to make

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[7] See https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial#:~:text=Section%20504%20of%20the%20Rehabilitation%20Act%20of%201973%20prohibits%20discrimination,on%20the%20basis%20of%20disability

[8] See https://pmc.ncbi.nlm.nih.gov/articles/PMC5104996/

[9] See https://pmc.ncbi.nlm.nih.gov/articles/PMC5104996/#:~:text=People%20with%20disabilities%20are%20largely,inclusive%20of%20people%20with%20disabilities.

[10] See https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00520

[11] See https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities#:~:text=Designation%2C%20new%20research%20program%20and,Pérez%2DStable.

[12] See https://www.ncd.gov/2023/02/24/notice-of-funding-opportunity-the-absence-of-people-with-disabilities-in-clinical-trials/

decisions that reflect those historic biases and stereotypes. How can we trust poorly trained AI to predict how a person with chronic conditions will respond to a new standard treatment or the number of hours of care assistance needed by someone with developmental disabilities? NIH must encourage more research to evaluate and prevent disability bias in algorithmic tools and AI applications. New best practices should be developed and tested to inform policymakers. That research should actively engage AI developers and deployers, and people with disabilities and their families in the effort to develop fairer AI.

Compounding Effects of Disadvantage

Research rarely examines how disability interacts with race, gender, socioeconomic status, and rural living.[13] These factors have a compounding effect on social disadvantage. For example, a study from the National Center for Biotechnology Information **"**demonstrated that racial/ethnic minority children with disabilities experience additional disparities in health care access outcomes that are greater than the sum of the effects from either characteristic alone."[14] These factors should be considered in the Strategic Plan for Disability Health Research and in all NIH research.

Mental Health & Disability

Many disabled individuals, particularly those with intellectual and developmental disabilities (IDD), struggle to access appropriate mental health care.[15] Many disabled individuals also experience medical trauma, leading to anxiety and avoidance of care. For example, "In the United States, the initial tests to diagnose Intellectual Disability (ID) were developed for the purpose of segregating people believed to be dangerous to society because of their "mental deficiencies".[16] This segregation of individuals with IDD has also contributed to a "siloing" of mental health and IDD systems, leading to a limited scope of mental health interventions available to individuals with IDD, with very few intervention modalities developed to be accessible or effective for people with IDD, particularly those with intellectual disability or who do not use speech to communicate. Certain disability communities, such as people with chronic pain, mobility impairments, or autism, also have higher suicide rates due in part to the mental health access disparity.[17]

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[13] See https://journals.sagepub.com/doi/full/10.1177/0891243218794648

[14] See https://pubmed.ncbi.nlm.nih.gov/33177369/

[15] See https://www.healthymindspolicy.org/research/barriers-to-care-for-people-with-co-occurring-mental-health-disorders-and-intellectual-and-developmental-disabilities#:~:text=Identifying%20barriers%20to%20behavioral%20health,providers%20and%20families%20or%20caregivers

[16] See https://pmc.ncbi.nlm.nih.gov/articles/PMC10050265/

[17] See https://www.urban.org/sites/default/files/2025-01/Screening%20Exploring%20Practice%20and%20Research%20Gaps%20for%20Suicidality%20Among%20Adults%20with%20a%20Disability.pdf

NIH should study effective ways to integrate mental health services into disability healthcare, investigate the unique risk factors for suicide among disabled populations and develop tailored interventions, and research best practices for providing trauma-informed care to disabled patients.

Medicaid, Home and Community-Based Services (HCBS), & Long-Term Services and Supports (LTSS)

Despite the disability community's strong preference for community-based living, some states still have policies that favor institutional care over access to HCBS.[18] Research needs to study the short, mid, and longitudinal health outcomes and quality of life of home-based care versus institutional care to encourage states to move their preferences to HCBS. More research is also needed into disparities in access to HCBS among different types of disability (particularly for people with mental and behavioral health disabilities), and based on race/ethnicity, language, and other demographic factors.

Public Health and Emergency Planning/Preparation

For too long, people with disabilities have been excluded from municipal, county, and regional collection of demographic information and detailed emergency planning and preparation. This directly leads to loss of life for people with disabilities, who are often less able to move quickly and independently out of danger in the event of such urgent disasters as fires or floods, and who have ongoing health needs that become urgent when medical devices, prescriptions, and power are easily lost in the aftermath of an emergency. Even when state or local laws are passed that mandate the full inclusion of disabled and older persons in emergency preparation, those laws are not implemented well or at all, it is too late to start thinking about the needs of people with disabilities after a tornado has touched down or a pandemic has begun. NIH must conduct research into municipal or county governments that have successfully implemented disability inclusive preparations and maintained these preparations over time, including the involvement of such critical third parties as Medicaid health plans or local public health departments or community non-profits, and act to disseminate this critical information.

Aging with a Disability

People with lifelong disabilities often experience aging differently, but research is limited. A Disability and health Justice Journal research from 2015 demonstrates these research gaps[19], however a decade has passed since the study and little progress on understanding

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[18] See https://www.macpac.gov/subtopic/home-and-community-based-services/#:~:text=Medicaid%20beneficiaries%20increasingly%20are%20receiving,2021

[19] See https://pmc.ncbi.nlm.nih.gov/articles/PMC3901947/

this issue has been made. For example, a 2015 Office of the Assistant Secretary for Planning and Evaluation (ASPE) report identified that individuals with IDD are at greater risk for early-onset dementia, yet little is known about best care practices or prevention.[20] NIH should therefore study the long-term effects of different disabilities on aging and healthcare needs and research early detection and treatment strategies for dementia in people with intellectual disabilities.

Reproductive & Maternal Health for Disabled Individuals

Many OB-GYN offices lack accessible equipment and training to treat disabled patients, and lack cultural competency in caring for expectant parents with disabilities.[21] Further, "Disability bias can be pervasive in assumptions about the lifestyle of a person with a disability, especially surrounding behaviors such as sexual activity."[22] Some disabled individuals also still face coercion or lack access to informed reproductive choices. Requests for a hysterectomy and/or tubal ligation not directly communicated by the patient are not always considered critically by practitioners.[23] For these reasons NIH should investigate pregnancy and parenting experiences for disabled individuals and address the care gaps that exist. NIH should also study the prevalence and impact of coerced sterilization policies and effective strategies to combat these practices.

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[20] See https://aspe.hhs.gov/reports/idd-dementia-0

[21] See https://pmc.ncbi.nlm.nih.gov/articles/PMC10953678/

[22] See https://pmc.ncbi.nlm.nih.gov/articles/PMC10953678/

[23] See https://pmc.ncbi.nlm.nih.gov/articles/PMC10486212/

Request for Information Response

Based on the above issues and recommendations we offer the below input on the framework's cross-cutting themes, strategic goals, potential opportunities, and additional areas for consideration to improve health outcomes for disabled populations.

Cross-Cutting Themes

We support the inclusion of Public Participation and Community Engagement, Accessibility, Complexity and Heterogeneity, and Dynamics of Disability as cross-cutting themes. However, we urge NIH to incorporate the following additional themes:

- **Health Equity and Intersectionality**: Research should recognize the compounding effects of disability in combination with race, gender, socioeconomic status, and rural living.
- **Trauma-Informed Care and Historical Context**: Many disabled individuals, particularly those with intellectual and developmental disabilities (IDD), have experienced medical trauma. Given the history of institutionalization, forced sterilization, and medical neglect in disabled communities, NIH should prioritize trauma-informed approaches in disability health research.

Strategic Goals & Additional Research Areas

We strongly support the four proposed strategic goals. Below are our recommendations for enhancements:

Goal #1: Support high-quality, innovative, and impactful research to improve the health and well-being of people with disabilities of all ages.

- **Tracking Longitudinal Health Outcomes:** Assessments must be individualized to capture the unique needs of each person over time and ensure that the NIH is capturing the full spectrum of experiences for people with disabilities. Standardized tools should be flexible enough to allow for customization based on individual circumstances. This may involve using open-ended questions, incorporating person-reported outcomes, and allowing respondents to provide additional context about their disabilities.
- **Accessible Healthcare Infrastructure**: NIH should fund research into universally designed medical devices (e.g., mammography machines, MRI equipment, exam tables, weight scales, and blood pressure cuffs) to address current accessibility gaps.
- **Bias in Medical Decision-Making**: NIH should investigate how provider bias and diagnostic overshadowing affect preventive care, and develop effective interventions to improve access.

- **Pain Management Disparities**: Research should explore disparities in pain management and the development of disability-inclusive guidelines for equitable treatment.

Goal #2: Build and sustain meaningful internal and external partnerships to promote disability health research.

- **Centralized Disability Research Hub**: Establish an NIH Office of Disability Health Research to coordinate interagency efforts, oversee funding opportunities, and serve as a primary point of contact for disability-related research initiatives, as well as the dissemination of research results. Sharing research findings with stakeholders will help spur related research and establish a sustainable baseline of health data that can be used to investigate the health impacts of other critical services needed by people with disabilities in areas such as transportation, education, employment, and HCBS.
- **Disability Community Leadership in Research**: Partnerships should prioritize leadership roles for people with disabilities, ensuring disabled voices are involved in shaping research priorities and methodologies.
- **Leverage Civil Rights Laws to Reduce the Impact of Disability Discrimination in Research:** Existing laws and regulations enacted under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act address many of the issues around bias, discrimination and lack of accessibility in healthcare covered in this comment. NIH should build information channels with federal enforcement agencies and their state counterparts to track compliance with relevant legal standards by health researchers so funding can be tailored to further incentivize compliance.

Goal #3: Promote engagement and inclusion of people with disabilities in the biomedical and behavioral research ecosystem.

- **Grant Review Committees and Advisory Councils:** The NIH should work to increase the number of people with disabilities on its grant review committees and advisory councils, and ensure their meetings are fully accessible. This will help the Institutes to be aware of the concerns of people with disabilities and enable them to direct grant funding to the most needed areas of research.
- **Mandating Disability Data Inclusion**: Demographic disability status should be mandated in all federally funded health research studies, including NIH clinical trials and surveys, to ensure comprehensive data collection on health disparities, including across populations that have multiple intersecting characteristics.
- **Inclusive Clinical Trials**: NIH should require that drug trials, mental health studies, and medical research include disability representation.

Goal #4: Develop a highly skilled scientific workforce that includes researchers with disabilities and researchers trained in disability health research.

- **Support for Disabled Researchers**: Researchers with disabilities bring critical lived experience and insights to the field. NIH should provide targeted funding, mentorship programs, and accessibility accommodations to recruit and retain disabled researchers.
- **Training in Disability Competency**: NIH should implement disability cultural competency training for researchers, clinicians, and staff to improve inclusion and equitable health outcomes, as well as practical guidance on budgeting and providing reasonable accommodations and policy modifications in the recruitment and research process.

Indicators to Measure Progress

To ensure accountability in implementing the strategic plan, NIH should track the following:

- Increasing success in reaching members of the disability community and disability. advocates about funding and grant initiatives and soliciting feedback on the standards for administering disability-inclusive research funding.
- Increase in funded studies on disability health disparities.
- Percentage of NIH-funded clinical trials that include and retain disabled participants throughout the trial.
- Number of researchers with disabilities receiving NIH funding.
- Implementation of accessibility standards in NIH research facilities and programs.

Effective Communication & Dissemination Strategies

To maximize the impact of the strategic plan, NIH should:

- Develop plain-language, accessible summaries of research findings and strategic plan updates.
- Engage disability-led organizations to co-design outreach efforts.
- Ensure research publications are available in accessible formats, including screen-reader-friendly PDFs, ASL interpretations, and Easy Read versions.

We appreciate NIH's recognition of people with disabilities as a population with health disparities in the strategic framework. By addressing these key research gaps, NIH can play a transformative role in achieving improved health outcomes for disabled individuals. We welcome the opportunity to collaborate and support these efforts.

Sincerely,

<u>Co-Chairs of the Consortium for Constituents with Disabilities Health Task Force</u>

Caroline Bergner, American Speech-Language-Hearing Association
David Machledt, National Health Law Program
Julie Schurman, Disability Belongs™
Greg Robinson, Autistic Self Advocacy Network