



## Progress Update, Year One: Health Equity Framework for People with Disabilities

In February 2022, after years of NCD's own research and following consultation with people with disabilities as well as a multidisciplinary team of disability and health policy experts, NCD released its [Health Equity Framework](#) (Framework). The Framework noted five core recommendations, among others, including the federal administrative designation of people with disabilities as a Health Disparities Population; the federal legislative designation of people with disabilities as a Special Medically Underserved Population under the Public Health Service Act; standardized disability competency training of medical professionals; improved health data collection for people with disabilities; and the availability and use of accessible medical equipment. Consistent with the intention to make periodic updates based upon new information received, NCD later updated the Framework in September 2022. During the year since its initial release, NCD has presented the Framework to numerous federal agencies as well as nongovernment organizations, and NCD is pleased to note several developments since its inception:

### Data:

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- The Office of the National Coordinator for Health Information Technology has put together [guidance](#) concerning the collection of data on disability status in electronic health records.
- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Interagency Committee on Disability Research (ICDR) perspective relaunched and reenvisioned the Disability Data & Statistics Working Group. This working group focuses on establishing greater coordination and collaboration related to disability statistics, terminology, and data collection. As part of the ICDR, this working group hosted their



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### Highlights

- **Five Core Components**

- Improved Data Capturing
- Comprehensive Disability Clinical-Care Curricula
- Health Disparities Population Designation
- Special Medically Underserved Population (SMUP) Designation
- Accessible Medical Diagnostic Equipment

- **38 Additional Components**



State of the Science on this topic of disability data and statistics in early February 2023.

- NIDILRR funded work published on disability data and measurement in the special issue on disability in [Health Affairs](#) (October 2023).
- NIDILRR funded a five-year [research grant](#) (FY22-FY26) specifically on Equity in Health and Functioning for Adults with Physical, Cognitive, Sensory, and Developmental Disabilities from Marginalized Communities.

### Disability Clinical and Competency Training:

- In 2022, House and Senate Appropriations Committee reports included language that encouraged the Health Resources and Services Administration to implement 42 U.S.C. 293(e), and develop a grant-based program in collaboration with NCD, professional societies, licensing and accreditation entities, health professions schools, experts in minority health and cultural competency, prevention, and public health; 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.).
- NCD continues to communicate with The Joint Commission (on hospital accreditation) concerning efforts they can make on this vital issue. The Joint Commission has conferred with NCD on the issue of diagnostic overshadowing/bias regarding populations of health disparities including people with disabilities and sent recommendations from NCD on the topic to their accredited hospitals in the form of [guidance](#) as noted in the June 22, 2022, issue of The Sentinel (a highly regarded complimentary publication of The Joint Commission).

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### **Health Disparity Population Designation:**

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- The National Advisory Council on Minority Health Disparities (NACMHD) established a working group in September 2022 to examine the state of knowledge and science around people living with disabilities and health disparities to determine whether to designate people with disabilities as a “Health Disparity Population.” Their work will culminate in an internal report to the National Institute on Minority Health and Health Disparities (NIMHD) by September 2023. They are also reviewing the 2018 National Academies of Science, Engineering and Medicine (NASEM) proceedings of a workshop on the same topic in consideration of commissioning a NASEM study on the topic. Chairman Gallegos made a presentation to the working group at its first meeting on December 13, 2022, and the group sent a request in January 2023 for further information, including information on disability bias and stigma. On February 3<sup>rd</sup> NCD responded with a detailed letter to the head of the working group.

### **Special Medically Underserved Population (SMUP) Designation:**

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- NCD continued to work closely with U.S. Rep. Seth Moulton’s office regarding the Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population Act of 2021 or the “HEADs UP Act of 2021.”
- In July 2022, U.S. Sens. Casey, Kaine, Duckworth, and Merkley introduced the Health Equity for People with Disabilities Act, which seeks to modify certain grants available to health centers that offer primary health services to medically underserved populations to ensure that members of such populations with disabilities receive accessible health services. While not seeking a SMUP designation, the bill would amend the Public Health Services Act to clarify that among the groups already classified as medically underserved populations, the

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needs of people with disabilities shall be a priority in order to reduce health disparities. Under this disability priority, health centers will also be able to use quality improvement grants to focus on improving accessibility accommodations and reducing barriers to care within their clinics, which may improve health care services to millions of Americans with disabilities.

### **Accessible Medical Diagnostic Equipment:**

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- NIH is working on developing accessible home medical tests for people with disabilities. NIH seeks improvements in the design of home medical tests in three focus areas: individuals who have low or no vision, individuals with fine motor skill difficulties, and older adults. Issues to be addressed include (1) the need for more intuitive test packaging, (2) need for clearer instruction, (3) need for easier maneuver test components (small test components, difficult to manipulate, frequent accidental test damage or contamination), and (4) need for more descriptive results (lack clear readout and lack a non-visual means of result interpretation). The goal is to ensure that tests that consumers use in their homes are accessible for people with vision disabilities and disabilities that impact dexterity.
- NCD held a roundtable in August 2022 regarding seat elevation coverage by Medicaid. Following NCD's roundtable, NCD wrote a letter to CMS concerning the need of CMS to cover elevated seat/power chairs and is submitting a summary of NCD's Roundtable on the subject as recommendations concerning this important matter. CMS released their proposed decision on February 15 to cover seat elevation systems in Group 3 power wheelchairs for beneficiaries who 1) use the systems to perform weight-bearing transfers to/from their wheelchair, and 2) undergo a specialty evaluation by a practitioner with experience in rehab wheelchair evaluations (which is standard practice already for any individual who is prescribed a seat elevator). The decision also includes a formal

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Benefit Category Determination that seat elevation systems qualify as Durable Medical Equipment because they are primarily medical in nature, which has previously been the holdup to coverage reviews. NCD is pleased with this decision, which conforms to some of the recommendations NCD has made but is also reviewing for additional recommendations.

- The Department of Justice plans to issue a Notice of Proposed Rulemaking in April of 2023 on Accessible Medical Equipment. The notice can be found [here](#).

### **Increased Industry Attention:**

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- Following Chairman Gallegos's April 2021 [article on health care inequities for people with disabilities](#) in Health Affairs, the October 2022 issue of Health Affairs focused entirely on disability and health in a variety of articles and podcasts and addressed many of the issues NCD addresses in its health equity framework. See: [Health Affairs | Vol 41, No 10](#)

### **Other Steps Taken Towards Health Equity:**

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- In March 2022, NCD released its report [Medicaid Oral Health Coverage for Adults with Intellectual and Developmental Disabilities - A Fiscal Analysis](#), in which NCD determined a modest return on investment in 11 of 12 states were they to increase Medicaid coverage for oral healthcare for people with I/DD where they currently provide no such benefits or emergency benefits alone. These savings would come vis-a-vis the money otherwise spent on preventable illness and in emergency rooms due to untreated dental problems.
- On March 31, 2022, CMS notified current Money Follows the Person (MFP) grantees (enabling more persons to transition to long-term services and supports in community settings) that it is increasing the reimbursement rate for MFP "supplemental

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services.” These services are now 100% federally funded with no state share. CMS also announced that it is expanding the definition of supplemental services to include additional services that can support an individual’s transition from an institution to the community, including short-term housing and food assistance.

- In November 2022, NCD released its report *Strengthening the HCBS Ecosystem – Responding to Dangers of Congregate Settings during COVID-19*. In the wake of the disproportionate death toll in congregate settings during the COVID-19 pandemic, this report examines weaknesses in the home- and community-based services (HCBS) ecosystem and outlines a roadmap to expand community living options to meet the needs of people with disabilities across the life span. The report builds upon findings in NCD’s 2021 Progress Report: *The Impacts of COVID-19 on People with Disabilities* (2021) and *Deinstitutionalization: Unfinished Business* (2012) and illustrates that each piece of the HCBS ecosystem must be working at full capacity to ensure that appropriate community living options and supports remain available to people with disabilities.
- The President signed the \$1.7 Trillion Consolidated Appropriations Act, 2023, which provides funding for the federal government through September 30<sup>th</sup> and extends funding for Medicaid Money Follows the Person (MFP) through September 30, 2027 at \$450 million annually (related to core component #17).

### **International Disability Health Equity:**

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- NCD submitted its health equity framework to the World Health Organization for their consideration as they finalize development of the newest WHO Global Report on Health Equity for persons with disabilities.

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**NCD welcomes feedback on its health equity  
framework.**

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To share your organization's or coalition's policy priorities or request a meeting with NCD, please email Nicholas Sabula, Public Affairs Specialist, at [nsabula@ncd.gov](mailto:nsabula@ncd.gov).

For more information on the National Council on Disability, please visit our website at [NCD.gov](http://NCD.gov).

