Framework to End Health Disparities for People with Disabilities

February 2022 (Latest Update April 2025)

Purpose

This Policy Brief provides rationale for the need of an all-of-government approach towards ending the health disparities of people with disabilities in the United States, a group made up of over 61 million people. Disability is a natural part of the human condition, which occurs across all age, gender, racial, ethnic, language and social groups.

Introduction

"Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhumane."

Dr. Martin Luther King, Jr., May 25, 1966

For decades, NCD has espoused that the predicate to a person's ability to live, learn, work, and earn, is to attain and maintain good health – mental, physical, and overall well-being. For people across all categories of disabilities, attaining and maintaining good health has been elusive for an unwelcoming healthcare system that for decades has failed 26% of the United States population, so much so that people with disabilities utilize the healthcare system for disease management instead of disease prevention and can even view the healthcare system as a source of potential harm. It is a paradigm that exists as a result of avoidable systemic barriers within our healthcare system;and the resistance to incorporate even minimal disability clinical care and competency training into medical, nursing, and other health professional schools, among other avoidable issues, which contribute to decades -long significant health disparities between people with disabilities and their nondisabled counterparts.

Health disparities between persons with disabilities and their nondisabled counterparts have not materially improved in the 16 years since NCD published its 2009 seminal report, The Current State of Health Care for People with Disabilities. Today, in the United States, if you are a person with a physical, intellectual,or developmental disability, your life expectancy is less than that of someone without disabilities.[1] You are more than three times as likely to have arthritis, diabetes, and a heart attack.[2] You are five times more likely to report a stroke, Chronic Obstructive Pulmonary Disease and

Highlights

- **Five Core Components**
  - Special Medically Underserved Population (SMUP) Designation
  - Health Disparities Population Designation
  - Comprehensive Disability Clinical-Care Curricula
  - Accessible Medical Diagnostic Equipment
  - Improved Data Capturing
- **43 Additional Components**

depression.[3] You are more likely to be obese.[4] You are significantly more likely to have unmet medical, dental, and prescription needs.[5] If you are a woman with a disability, you are likely to receive poorer maternity care and less likely to have received a Pap smear test or a mammogram.[6] If you are a pregnant woman with a disability, you have a much higher risk for severe pregnancy- and birth-related complications and eleven times the risk of maternal death.[7] If you are an adult who is Deaf or hard of hearing, you are three times as likely to report fair or poor health as compared to those who do not have hearing impairments.[8] As of 2022, if you had an intellectual disability, it was the strongest predictor for COVID-19 infection and the second strongest predictor for COVID-19 death.[9] If you live in a rural area, your disability appears to further worsen barriers to accessing healthcare.[10] These disparities are exacerbated if you are a person with a disability and a person of color. Studies have found that adults with disabilities in underserved racial and ethnic groups are more likely to report fair to poor health or that their health has worsened over the past year, compared with people without disabilities in the same racial/ ethnic groups and with non-Hispanic whites with disabilities.[11]

Core Components of NCD's Framework to End Health Disparities

Through its research, collaboration with experts, and consultation with members of the disability community, NCD's findings reveal five paramount policy issues on which the goal of ending health disparities of people with disabilities largely rely.

They include:

1. designating people with disabilities as a Special Medically Underserved Population (SMUP) under the Public Health Services Act;
2. designating people with disabilities as a Health Disparity Population under the Minority Health and Health Disparities Research and Education Act (**UPDATE:** designated September 2023);
3. requiring comprehensive disability clinical-care curricula in all US medical, nursing and other healthcare professional schools and requiring disability competency education and training of medical, nursing and other healthcare professionals;
4. requiring the use of accessible medical and diagnostic equipment (**UPDATE:** required as of July 8, 2024); and
5. improving data collection concerning healthcare for people with disabilities across the lifespan.

Special Medically Underserved Population Designation (SMUP)

To end the health disparities of people with disabilities, it is critical that people with disabilities be legally identified as a SMUP under the Public Health Service Act,

To achieve an end to health discrepancies for people with disabilities, it is critical that people with disabilities be legally identified as a SMUP under the Public Health Service Act…

with the corresponding benefits associated with that designation. These benefits could include:

- federal funding for health centers and public health infrastructure such as Federally Qualified Health Centers;
- eligibility to apply for federal funding to develop and operate Community Health Centers; and access to loan repayment and training programs in the Health Resource Services Administration's (HRSA) Workforce Development and Training Programs, including the national Health Service Corps Scholarships;
- incentives for physicians to treat the designated population in the form of higher Centers for Medicare and Medicaid Services (CMS) reimbursement rates for physician services;
- and preference given to research at federal agencies, including the National Institutes of Health, that studies medically underserved populations.

Typically, Medically Underserved Population designations by HRSA require population groupings based upon geography, which is not an applicable means of grouping for providing appropriate healthcare to the national community of people with disabilities, who are a part of every American community. Accordingly, people with disabilities must be designated by Congress as a Special Medically Underserved Population through a revision of Section 330 of the Public Health Service Act.

Health Disparities Population Designation

In the absence of SMUP designation, and regardless of whether people with disabilities are designated as a SMUP, in September 2023, the National Institutes of Health announced and began to implement that people with disabilities were designated as a "Health Disparity Population" under the Minority Health and Health Disparities Research and Education Act of 2000 (MHHDREA). Under that Act, the Director of the National Institute on Minority Health and Health Disparities (the Institute), after consultation with the Director of the Agency for Healthcare Research and Quality, may designate a population as a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.

This designation is necessary and appropriate to improve both coordinated research and appropriate healthcare for people with disabilities. With that designation, among other things, the Director of the Institute is required to establish centers of excellence for research, education, and training, and work with qualified health professionals to engage in health disparities research in exchange for which the Federal Government will agree to repay, for each year of engagement in such clinical practice or research, not more than $35,000 of the principal and interest of the educational loans of such health professionals. The

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goal of the health disparities research is to better understand the causes of the disparate health outcomes experienced by people with disabilities to successfully develop policies and interventions whereby the disparities are eliminated, often resulting in better life expectancy, quality of life, and focus on prevention versus management, consistent with the goals of the Make America Healthy Again initiative.

Comprehensive Disability Clinical-Care Curricula and Disability Competency Training

The lack of comprehensive disability clinical-care education and disability competency training among medical, nursing and other healthcare professionals can perpetuate discrimination in healthcare against people with disabilities and significantly contributes to the disparate health outcomes of people with disabilities. The inordinate majority of federally financed medical, nursing, healthcare professional, and allied health professional schools, as well as post-graduate residency and fellowship programs, do not incorporate disability clinical-care into curricula or training. NCD believes that must change.

Physicians often lack the knowledge, experience, and skills to distinguish clinical concerns arising from disability from those related to other health conditions.

One's apparent disability – even when unrelated to the reason for one's health care visit – can result in diagnostic overshadowing the clinical concern and can have negative impact during the health care visit. This lack of familiarity and understanding of disability is detrimental for quality of care, contributing to delays in diagnosis and treatment, unsafe care, and inequities in care. Furthermore, and also due to a lack of training and familiarity, people with disabilities are sometimes viewed as asexual.[12] These assumptions may contribute to the finding that women with disabilities undergo colon cancer screening at similar rates as their nondisabled peers, but experience disparities in breast cancer and cervical cancer screening.[13] The sexual health of women with intellectual disabilities is particularly ignored in terms of screening for breast and cervical cancer.[14]

The COVID-19 pandemic has unmasked the extent to which bias against people with disabilities affects treatment decisions. Crisis standards of care were enacted in many jurisdictions which were facially discriminatory against people with disabilities. States including Alabama, Arizona, Kansas, Pennsylvania, Tennessee, Utah and Washington established crisis standards of care that expressly based triage decisions on normative quality-of-life judgments or excluded from treatment patients who require assistance with activities of daily living or those with certain conditions like severe or profound intellectual disabilities, moderate to severe dementia, and other pre-existing health conditions. Healthcare providers were forced to consider the possibility of medical scarcity and the need to ration life-saving medical treatments and, in response, many health systems employed protocols that explicitly discriminated against people with pre-existing disabilities by de-prioritizing them.[15]

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An abundance of research indicates the lack of disability competency and interdisciplinary training among medical professionals contributes to the health disparities of people with disabilities across the nation.[16] While some medical schools in the US do provide disability competency training, the overwhelming majority do not.,[17] Standard, comprehensive disability clinical-care education and training of medical, nursing, and other healthcare professionals is essential for a better educated healthcare workforce trained with an understanding of disability as a natural part of the human condition versus conditions that must be avoided, prevented or fixed. Comprehensive disability clinical-care competency should be woven into the curricula requirements of all US undergraduate medical, nursing, healthcare professional, and allied health professional education, as well as post-graduate residency and fellowship programs that are conducted in over 1,100 teaching hospitals. Section 5307 of the Patient Protection and Affordable Care Act provides the legislative authority for the Secretary of HHS to fund the development of and to disseminate model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professions schools and continuing education programs.[18],[19] Section 5307 does not, however, require adoption and implementation of such curricula. NCD recommends that it should so that medical professionals can become adequately prepared to interact with and provide the same standards of care to disabled patients as their nondisabled patients.

Recent precedent exists for such a useful policy initiative within the field of oral healthcare training. Beginning in 2020, the Council on Dental Accreditation (CODA) revised its standards, and now mandates that dental students must be trained in the assessment, management and treatment of patients with "[sic] special needs" ("special needs" is described by CODA's published intent as "those patients whose medical, physical, psychological, cognitive, sensory, or social situations make it necessary to consider a wide range of assessment and care options . . . these individuals include, but are not limited to, people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly").[20] Much the same way these requirements were developed within the oral healthcare field as needed for compliance with Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, it is equally vital that disability competency training be required of all medical healthcare professionals, not only to comply with those same laws but to equip medical professionals to have confidence when interacting with a patient with a disability and better treat their health concerns.

NCD recommends the creation of model comprehensive disability clinical-care competency curricula by HHS that encompasses the framework we set forth below for use and adoption by those schools that do not have the capacity to develop their own curricula. For those schools that endeavor to create their own curricula, it should also encompass the following framework.

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Model Disability Clinical-Care Competency Curricula Framework

The development of model curricula should include the following:[21]

- Competency 1: Contextual and Conceptual Frameworks on Disability
- Competency 2: Professionalism and Patient-Centered Care
- Competency 3: Legal Obligations and Responsibilities for Caring for Patients with Disabilities
- Competency 4: Teams and Systems-based Practice
- Competency 5: Clinical Assessment
- Competency 6: Clinical Care over the Lifespan and during Transitions
- Competency 7: Effective Communication
- Competency 8: Advocacy

With respect to the Effective Communication competency, while implied in the preceding six competencies, NCD recommends the deliberate emphasis of the need for effective, sensitive, and ongoing bi-directional communication. While communication might appear to be intuitive, communicating with patients with disabilities may present challenges which can compromise outcomes, particularly as providers often must reach judgments about patients' conditions and make decisions about treatment under severe time pressure. The acquisition of active listening skills and non-verbal symbolism must be emphasized and included in teaching communication competencies. Communication provides the framework for an empathetic connection between the patient and the provider. Effective communication is bi-directional between patients and healthcare systems. If either the patient or health care provider lacks clear understanding of the information conveyed, the delivery of care is compromised.[22]

In addition, a vibrant competency-based curriculum to teach medical, nursing, and other healthcare professional students the basic clinical skills is needed to effectively treat patients across all categories of disabilities and must include: respectful interactions (etiquette and awareness); problem-solving (i.e., scheme-based) approach to history taking and physical examination; development of clinical reasoning; formation of an initial diagnostic plan; interpretation of basic diagnostic studies; performance of select procedures; provision of counseling and feedback; and skills to articulate clinical case presentation. Furthermore, real time interaction with patients with various disabilities, self-advocates, families, direct support professionals, and caregivers is necessary. The students must:

- be instructed to become competent in the creation of the "patient narrative" as a means of appreciating the psychosocial determinants of the disease and the receptivity and understanding of the goals of the treatment plan;
- learn to apply principles of social-behavioral sciences to provision of patient care, including assessment of the impact of psychosocial and cultural influences on health, disease, care seeking, care compliance, and barriers to and attitudes toward care;

Often positive patient outcomes are a direct result of actions taken by the provider as a practiced patient advocate.

- demonstrate insight and understanding about emotions related to the disability experience that allow one to develop and manage interpersonal interactions;
- demonstrate compassion, integrity, and respect for others;
- learn to appreciate the impact of the disabling condition and how it influences the patient's resilience, compliance, relationships, goals, lifestyles, and outcomes;
- be able to identify, incorporate, and utilize community resources, specialty treatment clinics, centers of excellence, and syndrome and disease specific guidelines; and
- learn and understand the process of supported decision-making as an alternative paradigm to guardianship, which empowers persons with cognitive disabilities, by ensuring they participate in their own health care and are the ultimate decision-makers.

Finally, with respect to the Advocacy competency, the curriculum must promote and teach students the tactics and practices in becoming a patient advocate. In the traditional medical care dyad, the physician interacted singularly with the patient, and the physician's role as an advocate was confined to the limits of the consultation room. The expectation of their advocacy was to ensure that the patient received the highest level of care available at that time. Today's complex healthcare system is increasingly fragmented. Physicians must now advocate for their patients beyond the confines of the examination room. They must justify, defend and appeal specific diagnostic tests, medications outside the formularies, referrals, transitionary care, sites of care, deviations from treatment guidelines, and requests for durable medical equipment, and complex rehabilitation technology, among other things. They need to learn, practice and utilize skills as negotiators, educators, advocates, problem solvers, resource analysts, counselors, intermediators, facilitators, historians and narrators. These skills require formal education and training, in the same sphere as clinical reasoning. Often positive patient outcomes are a direct result of actions taken by the provider as a practiced patient advocate. Physician advocacy has impact on health promotion, disease prevention, care burden, economics and overall community health.

Accessible Medical and Diagnostic Equipment

People with paralysis and mobility disabilities experience systemic barriers throughout the healthcare system in receiving care comparable to their nondisabled counterparts. This is largely the result of the lack of accessible medical diagnostic equipment, such as height adjustable examination tables, height adjustable examination chairs, wheelchair accessible weight scales, and accessible diagnostic equipment.[23] Without widespread availability of height adjustable examination tables, accessible mammography equipment, accessible weight scales and lift equipment to facilitate transfers, among other accessible medical and diagnostic equipment, people with mobility disabilities will remain

less likely to receive recommended, routine, preventive health care services—like cervical cancer screening, colorectal cancer screening, obesity screening, and breast cancer screening.[24] These requirements are a vital part of the effort to end the health disparities of people with disabilities. **UPDATE --** In May 2024, the Department of Health and Human Services finalized requirements for the accessibility of medical diagnostic equipment used by public and private entities that receive funding from HHS beginning July 8, 2024.

Improving Data Collection Concerning Healthcare for People with Disabilities across the Lifespan

With due consideration of privacy concerns, it is necessary that indicators of disability status be included in all public health surveillance systems, Medicare and Medicaid data, and the National Health Interview Surveys to assess the impact of public health threats and events on populations with disabilities so that the effectiveness of planning and response can be assessed and improved upon. This data should be captured across individuals' lifespans and be inclusive of all ages and times of onset of disability. Health care organizations must also systematically collect and record patients' disability status and needed accommodations within electronic health records (EHR) as a means of planning and providing informed, quality health care. Uniform disability identifiers must be included in EHR, death certificates, and insurance claims captured for all patients even if treatment sought is unrelated to the person's disability.

Part and parcel of the lack of sufficient data concerning people with disabilities is the information gap overlooked by government agencies. Standardized disability identifiers are necessary across federal surveys. Further, numerous federal agencies note the need to address issues of concern for people with disabilities in their periodic strategic plans, yet not enough has been produced concerning what, if anything, has been achieved for people with disabilities. Receiving such information is a necessary step towards identifying what problems remain unsolved and what can be done to rectify them.

NCD supports federal agency efforts to include disability status in healthcare data collection, and recommends that the National Academies of Science, Engineering and Medicine (NASEM) conduct a comprehensive study and report of HHS's data collection systems and practices, and any data collection or reporting systems required under any of the programs or activities of HHS, relating to the collection of data on disability. This should include other federal data collection systems, such as the Social Security Administration (SSA), with which HHS interacts to collect relevant data on disability. The linkage of CMS and SSA data for research purposes is vital and must be prioritized through adequate funding.

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Additional Components of NCD's Framework to End Health Disparities of People with Disabilities

In addition to the five core components of NCD's Framework to End Health Disparities of People with Disabilities, NCD further recommends the following:

1. Establish a National Center on Disability, Health, and Health Disparities within the National Institutes of Health in collaboration with the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR). The Center should have authority for joint funding and address health disparities by conducting and supporting research, conducting training, disseminating information, and developing other programs with respect to health conditions and the elimination of health disparities of persons with disabilities. The Center should also explore the impacts of interventions designed to address health disparities on outcomes. The work of this proposed Center must be prioritized through adequate funding. (Requires legislative action.)

2. In the alternative, amend the Minority Health and Health Disparities Research and Education Act of 2000, PL 106–525, to require the National Institute on Minority Health and Health Disparities (NIMHD), formally known as the National Center on Minority Health and Health Disparities, and sufficiently fund it to conduct and support research, training, dissemination of information and other programs with respect to health conditions and the elimination of health disparities of persons with disabilities. (Requires legislative action.)

3. Require each recipient of federal financial assistance to publicly report and disclose crisis standards of care and healthcare rationing policies and require a period of public comment from the community the recipient services. (Requires administrative action through HHS Office of Civil Rights.)

4. Issue regulations clarifying the obligations of covered entities under Section 504 of the Rehabilitation Act with respect to the withholding of life-sustaining care, medical futility determinations and organ transplant discrimination, organ donation, and other areas relevant to health care or disability discrimination by HHS entities. The regulations should ensure neither long-term survivability or quality of life is taken into account in making healthcare determinations. (Requires administrative action through the HHS Office of Civil Rights.) (**UPDATE:** in May 2024, HHS Office of Civil Rights finalized a final rule addressing these concerns.)

5. Create mandatory national guidelines regarding the need for medical offices, clinics, and hospitals to adopt "sensory friendly" environments to assist

patients with sensory processing disorders to acclimate to the sensory-aggressive environments these sites promote. (Requires administrative action through DOJ and the HHS Office of Civil Rights).

6. Provide mandatory industry guidance, including recommended policies, training and best practices, to address the needs of people disabled by exposure to low level chemical, electromagnetic, and other environmental exposures that preclude access to care and treatment at medical, dental and at other providers' offices, hospitals, surgical centers, and other healthcare and healthcare–related facilities, as a result of their use of chemical, fragranced and other scented products, and also as a result of the usage of wireless communications and electrical technologies and other sources of non-ionizing radiation, which may trigger disabling and life-threatening cardiac, respiratory, neurological, and other adverse physical reactions. (Requires administrative action through HHS Office of Civil Rights, and further research concerning this matter should be conducted by the FDA, NIH, HHS, and HUD.)

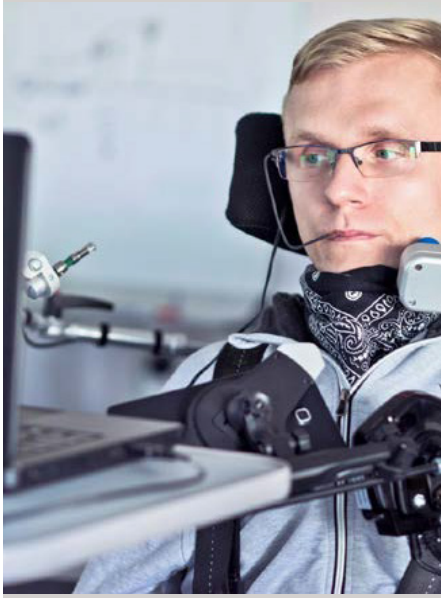
7. Develop industry guidance to behavioral health facilities and hospitals with behavioral health units regarding the prohibition of the use of exclusionary criteria that excludes from inpatient and outpatient programs qualified patients with intellectual and developmental disabilities, and patients with mobility disabilities who utilize mobility devices and who may need assistance with activities of daily living. (Requires administrative action by HHS Office of Civil Rights and DOJ.)

8. Mandate a blanket prohibition on the use of Quality Adjusted Life Years by any federal agency, or recipients of federal financial assistance from the Department of Health and Human Services, both directly and through third-party assessments.[25] (Requires legislative action.)

9. Create an "essential disability benefits" list, in collaboration with the disability community, inclusive of home- and community-based services, required of all insurance products (public and private), in the same way that the Affordable Care Act articulated an essential benefits package for all health insurance products. (Requires legislative action.)

10. Establish a national Medicaid buy-in program to eliminate the benefits cliff and enable Medicaid enrollees with disabilities to retain employment supports and other Medicaid coverage benefits as they seek employment and are not deterred from pursuing or accepting increases in their earnings. (Requires legislative action.)

11. Mandate Medicare coverage for low-vision devices, which can include a broad range of assistive technology other than traditional eyeglasses and



contact individuals with visual impairments resulting from a range of medical eye conditions. (Requires administrative action through CMS.)

12. Require Medicare coverage of seat elevation, standing, balancing and other features permitting wheelchairs to drive up and down steep inclines and over a wide variety of terrain, including climbing up and down stairs in power wheelchairs (Group 3 Complex Rehabilitation Technology). (**UPDATE:** in 2023 CMS announced that Medicare will now cover seat elevation devices for power wheelchairs.)

13. Develop Medicare coverage for additional dental services under the medically necessary definition for oral care (requires administrative action through CMS) or create a more comprehensive benefit (Requires legislative action).

14. Require Medicare coverage for comprehensive hearing health. (Requires legislative action.)

15. Provide permanent parity in Medicare coverage of wheelchair accessories (including seating systems) and seat and back cushions for complex, rehabilitative manual wheelchairs, and certain manual wheelchairs (just as is provided for complex rehabilitative power wheelchairs), as specified in section 106 of the Further Consolidated Appropriations Act, 2020. (Requires legislative action.)

16. Provide extensive adult oral health benefits through Medicaid to people with intellectual and developmental disabilities who otherwise do not have access to such benefits (which could potentially save states' costs through preventive care versus emergency room care costs). (Requires legislative action.)

17. Implement improvements to, and permanently fund, home- and community-based services (HCBS) sufficiently to ensure that no Medicaid beneficiaries are forced to accept services in institutional or segregated settings due to a lack of HCBS. (Requires administrative action through CMS or legislative action.)

18. Establish a Direct Support Professional standard occupational classification. (Requires administrative action by the US Department of Labor.).

19. Issue guidance updating requirements for mental health peer and family supports as Medicaid-funded services and encourage states to expand these services. (Requires administrative action through CMS.)

20. Issue guidance clarifying how to cover supported employment services and housing-related services and encourage states to expand these services. (Requires administrative action by CMS.)

21. Stop issuing waivers of the Medicaid Institute for Mental Disease (IMD) rule that allow states to receive federal Medicaid reimbursement for services in mental health institutions. (Requires administrative action through CMS.)

22. Enforce rules requiring federally funded managed-care organizations and health plans to adopt policies, procedures, and practices requiring the transparency of approvals/denials of requests for complex rehabilitation technology. (Requires administrative action through CMS.)

23. Encourage health plans to include a person with disability in the peer review process. (Requires administrative action through CMS.)

24. Require that municipal park districts and hospitals that receive federal financial assistance must provide in their fitness facilities inclusive, commercial-grade strength and cardio equipment for use by persons with mobility disabilities while they remain in their wheelchairs, and which can be used independently by persons who are blind or with low vision. (Requires administrative action through HHS Office of Civil Rights and DOJ.)

25. Adopt the heightened "primary consideration" requirement under the Title II regulations for public entities, 28 C.F.R. §35.160(b) as part of the effective communication standards under the ADA Title III regulations, 28 C.F.R. §36.303(c). (Requires administrative action by DOJ.)

26. Incorporate into the effective communication standards under the ADA Title II and Title III requirements for on-site American Sign Language (ASL) interpreters for patients requesting ASL interpreters during the defined "vital encounters" as consistently required in DOJ enforcement actions and settlements. (Requires administrative action by DOJ.)

27. Engage in vigorous enforcement of the Americans with Disabilities Act integration mandate and the Olmstead decision. (Requires administrative action by DOJ.) Stop issuing waivers of the Medicaid Institute for Mental Disease (IMD) rule that allow states to receive federal Medicaid reimbursement for services in mental health institutions. (Requires administrative action through CMS.)

28. Issue guidance to covered entities stating that the COVID-19 pandemic cannot be used as a reason to stop affording opportunities to transition out of institutional settings, and offer strategies to facilitate transitions in light of the impact that the pandemic has had on community service providers. (Requires administrative action by DOJ.)

29. Extend health insurance coverage of the Civilian Health and Medical Program of the US Department of Veterans Affairs (VA) to dependents of catastrophically disabled veterans until age 26 (to obtain consistency for

dependent coverage as provided under the Affordable Care Act). (Requires legislative action.)

30. Establish a five-year grant program to improve the monitoring of VA mental health and substance abuse treatment programs. The VA should award a grant to four protection and advocacy agencies. Each agency should investigate and monitor VA facilities care and treatment of veterans with mental health conditions or substance use disabilities. (Requires administrative action by the VA or legislative action.)

31. Create and administer a plan to address healthcare and benefits for veterans with conditions related to exposure to toxic substances, including requiring the VA to furnish consultation, testing, and treatment to certain veterans exposed to such substances. (**UPDATE:** enacted in August 2022.)

32. Establish standards and requirements for non-Department mental healthcare providers who participate in the VA Community Care program. (Requires administrative action through the VA or legislative action.)

33. Provide coverage for infertility treatment and standard fertility preservation services to qualified veterans. (Requires administrative action through the VA or legislative action.)

34. Implement programs, policies, and reports related to VA transition assistance, suicide care, mental health education and treatment, healthcare, and women veteran care. (Requires administrative action through the VA.)

35. Expedite implementation of Phase II of the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC).[26] (**UPDATE:** implemented in October 2022.)

36. Establish regulations requiring that intermediate and high-risk medical devices with a digital interface provide a blind or low-vision user access to the same services and information, and generally the same ease of use, as provided to a user who is not low-vision or blind. (Requires administrative action through the FDA.)

37. Ensure that telehealth platforms and electronic health records software comply with the accessibility requirements of Section 508 of the Rehabilitation Act of 1973, including requiring telehealth platforms to have the capacity for an on-screen sign language interpreter and captioning. (Requires administrative action through HHS, DOJ, and CMS.)

38. Provide robust Medicare and Medicaid reimbursement rates for the use of qualified (as such term is defined in the ADA regulations) and licensed (where required by the laws of a jurisdiction) on-site sign language interpreters and

certified deaf interpreters. Robust reimbursement rates should also extend to mental health therapists and other providers who are qualified and licensed sign language interpreters when communicating to persons via sign language. (Requires administrative action through CMS in collaboration with respective states action.)

39. Improve access to services for persons with limited English proficiency to state that services funded and provided by the federal government through oral communication also be made accessible to otherwise eligible persons that are deaf or hard of hearing and communicate through American Sign Language. (Requires administrative action by the President of the United States.)

40. Recognize genetic counselors as health professionals who can receive reimbursement through Medicare and incentivize Medicaid payments for genetic counseling as an independent health care service rather than only reimbursing genetic testing to create an infrastructure of professionals who can discuss complex genetic technology and prenatal interventions. (Requires administrative action through CMS.)

41. Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008). (Requires legislative action.)

42. Protect and establish laws such as the Genetic Information Nondiscrimination Act to prohibit health insurers and other entities from discriminating against families for choices regarding prenatal interventions. (Requires legislative action.)

43. Pass the Access to Genetic Counselor Services Act H.R. 3876 to expand access to genetic counseling services by providing for coverage under Medicare for genetic counseling services that are furnished by genetic counselors. (Requires legislative action.)

Conclusion

NCD's recommendations are intended to help end health disparities faced by people with disabilities in the healthcare system. Far from exclusionary in its pursuit, NCD views its policy advice pertaining to health as the predicate to people with disabilities being able to live, learn, and earn on an equal basis with others.

NCD welcomes feedback on this health disparities framework.

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.

Endnotes

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