



November 13, 2023

Melanie Fontes Rainer, Director
Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

RE: Notice of Proposed Rulemaking on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities; Docket No: 2023-19149, RIN: 0945-AA15

Dear Director Fontes Rainer:

The National Health Council (NHC) appreciates the opportunity to provide comments on the Department of Health and Human Services (HHS) proposed rule, *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*.

Created by and for patient organizations over 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, equitable, and sustainable health care. Made up of more than 155 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses and organizations representing biopharmaceuticals, devices, diagnostics, generics, and payers.

The NHC commends the Department for its proactive efforts to enhance the civil rights of individuals with disabilities through the proposed amendments to section 504 of the Rehabilitation Act of 1973. We recognize and support the Department's objective to update and clarify existing requirements, effectively prohibiting discrimination on multiple fronts including medical treatment, value assessments, and accessibility to digital platforms and medical equipment. These updates are not only timely but also in alignment with the NHC's core mission to advocate for patient-centered, equitable, and high-value health care. We believe that certain areas within the proposal could benefit from further refinement and clarification. In the subsequent sections, the NHC will offer general comments and recommendations aimed at ensuring the comprehensive and equitable implementation of these regulatory updates, with responses to specific questions starting on page 15.

Nondiscriminatory Criteria

The NHC strongly supports the provisions under the newly designated § 84.68(b)(3), emphasizing the prohibition of discriminatory methods in the allocation of scarce medical resources. We commend the attention given to ensuring that individuals with disabilities are not deemed lower priority during crises, specifically in the context of methodologies like the Sequential Organ Failure Assessment (SOFA) and the Glasgow Coma Scale (GCS). The COVID-19 pandemic illuminated how standard resource allocation strategies could inherently discriminate against individuals with disabilities. A study published in the *Journal of Health Politics, Policy, and Law* pointed out that allocation frameworks like SOFA could inadvertently discriminate against individuals with certain pre-existing conditions or disabilities.¹

We support the proposed § 84.68(b)(7) for reasonable modifications to assessment tools like the GCS, which currently can inaccurately assess short-term mortality risks in individuals with specific disabilities such as autism or cerebral palsy.² Adapting these tools is crucial for avoiding biased care allocation and ensuring that symptoms or standard responses are not misinterpreted. This can help prevent skewed prioritization in critical care situations, by acknowledging that certain conditions may influence assessment results without actually affecting short-term mortality.

To effectively implement these non-discriminatory guidelines, there is an urgent need for comprehensive training programs for health care providers. A study revealed that health care providers often lack the necessary training to effectively care for individuals with disabilities, underscoring the need for comprehensive training programs.³ Training is required to sensitize health care professionals to the nuances of various disabilities and provide clear guidelines on how to adapt assessment tools accordingly. This training should also emphasize the ethical implications of resource allocation and instill a commitment to equality and non-discrimination.

Furthermore, the NHC recommends that experts in various disabilities be involved in the development of crisis care protocols. Their insights would be invaluable in creating guidelines that are truly inclusive and non-discriminatory. This collaborative approach would help in designing assessment modifications that are scientifically sound and do not compromise the individual's chance of survival.

Finally, there must be transparency in how these allocation protocols are developed and implemented. We suggest establishing a review committee, including representatives from the disability community, to monitor compliance and address potential grievances.

¹ Ne'eman, A., Stein, M., Berger, Z., and Dorfman, D. (2021). The treatment of disability under crisis standards of care: an empirical and normative analysis of change over time during COVID-19. *Journal of Health Politics, Policy, and Law*, 46(5), 831-860.

² Ibid.

³ Iezzoni, L., Rao, S., Ressler, J., Bolcic-Jankovic, D., Agaronnik, N., Lagu, T., Pendo, E., and Campbell, E. (2022). US physicians' knowledge about the Americans with Disabilities Act and accommodation of patients with disability. *Health Affairs*, 41(1), 96-104.

This step would ensure accountability and foster greater trust in the health care system among all stakeholders.

While the NHC recognizes the challenges involved in allocating scarce resources during medical emergencies, it is imperative to uphold the principles of fairness, equity, and non-discrimination embedded in our health care system. These values must not be compromised, even in crisis situations. The measures outlined in § 84.68(b)(3) and § 84.68(b)(7) are commendable steps towards safeguarding the rights of individuals with disabilities, and we advocate for their strict and conscientious implementation.

Medical Treatment

The rule's emphasis on prohibiting disability-based discrimination in medical treatment is a significant step forward. Discriminatory beliefs, such as those illustrated in the provided examples regarding HIV patients or those with psychiatric disorders, must be directly addressed and eliminated from medical practices. The acknowledgement that the language of Section 504 is clear and broad sets a strong foundation for the rule. The delineation between circumstances where individuals seek treatment for the underlying disability versus a separately diagnosable condition provides clarity. This is crucial in preventing discrimination based on medical treatments that might be tied to the disability. For instance, individuals with psychiatric disorders often face discrimination in various aspects of health care. A study reveals that people with severe mental illness die 10 to 20 years earlier than the general population, often due to inadequate medical care.⁴ We applaud the rule's recognition of the need to defer to reasonable medical judgment while ensuring that such judgment is not biased. Studies show that physicians' biases can affect their clinical decisions, which can lead to disparities in medical treatment, and a recent systematic review and meta-analysis has found negative biases towards people with disabilities.^{5,6,7} Discrimination, whether based on biased medical judgment or not, should never be permissible under Section 504 or any other statute. We fully support the rule's intent to eliminate discriminatory practices in medical treatment. We appreciate the detailed explanations provided and believe that these changes, once implemented, will significantly improve the medical care landscape for individuals with disabilities.

The NHC wholeheartedly supports the Department's commitment to rectifying past and ongoing injustices related to the discriminatory provision of medical treatment to

⁴ Walker, E., McGee, R., and Druss, B. (2015). Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry*, 72(4), 334-341.

⁵ Van Ryn, M., and Burke, J. (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine*, 50(6), 813-828.

⁶ Gopal, D., Chetty, U., O'Donnell, P., Garjria, C., and Blackadder-Weinstein, J. (2021). Implicit bias in healthcare: clinical practice, research, and decision making. *Future Healthcare Journal*, 8(1), 40-48.

⁷ Antonopoulos, C., Sugden, N., and Saliba, A. (2023). Implicit bias toward people with disability: a systematic review and meta-analysis. *Rehabilitation Psychology*, 68(2), 121-134.

persons with disabilities. The proposed provision rightly aims to ensure that persons with disabilities are not deprived of this fundamental right. Any provision of medical treatment that undermines the autonomy or dignity of an individual based on disability is unjustifiable and should be eradicated. We understand that there may be legitimate medical reasons for providing different treatment to a person with a disability compared to a person without. The NHC believes it is essential for such distinctions in treatment to be based strictly on medical evidence and patient-specific factors, ensuring no discriminatory biases influence clinical decisions.

The historical overview provided by the Department is a sobering reminder of the grave injustices faced by persons with disabilities. For instance, a 2018 report by the National Council on Disability highlighted the persistent disparities in health care that people with disabilities face, citing instances where individuals with disabilities were denied necessary medical care based on prejudiced attitudes and lack of provider knowledge.⁸ Addressing these injustices directly in the proposed regulations sends a powerful message that such violations of human rights will not be tolerated. The NHC urges the Department to maintain its steadfast stance against such practices.

The NHC supports the core tenet of the proposed § 84.56(b)(1), which stipulates that medical treatment should not be denied or limited based on misconceptions, stereotypes, or biases about disabilities. The provision rightfully identifies and addresses factors that historically have subjected individuals with disabilities to discriminatory medical practices. According to a 2017 report by the National Council on Disability, individuals with disabilities often face significant barriers in accessing health care services, including discriminatory attitudes from health care.⁹ Proposed paragraph 84.56(b)(1)(i) correctly underscores the importance of eliminating medical decisions based on bias or stereotypes. Denying patients treatment options due to prejudiced beliefs undermines equitable health care access. We commend the clarity and thoroughness of proposed paragraph (b)(1)(ii).

Discriminatory attitudes have real-world consequences, as provider discrimination is associated with worse health care access for individuals with disabilities.¹⁰ Decisions about medical treatments should be rooted in the effectiveness of the treatment, not influenced by societal judgments. We appreciate that this provision does not force clinicians to offer treatments outside their expertise. However, ensuring that a referral

⁸ National Council on Disability. (2018). *National disability report: a progress report. Has the promise been kept? Federal enforcement of disability rights laws*. National Council on Disability. https://ncd.gov/sites/default/files/Documents/NCD_Federal-Enforcement_508.pdf

⁹ National Council on Disability. (2017). *National disability report: a progress report*. National Council on Disability. https://ncd.gov/sites/default/files/NCD_A%20Progress%20Report_508.pdf

¹⁰ Lagu, T., Haywood, C., Reimold, K., DeJong, C., Sterling, R., and Iezzoni, L. (2022). 'I am not the doctor for you': physicians' attitudes about caring for people with disabilities. *Health Affairs*, 41(10), 1387-1395.

process is devoid of discriminatory practices is imperative, and we commend the Department for clarifying this stance.^{11,12}

The NHC commends the Department for including provisions in § 84.56(b)(2) that prohibit the denial or limitation of clinically appropriate treatment based on an individual's underlying disability. It is critical to ensure that individuals with disabilities are afforded the same access to medical treatment for separately diagnosable symptoms or conditions as those without underlying disabilities. According to the Centers for Disease Control and Prevention (CDC), as of 2023, 27 percent of U.S. adults have a disability that impacts major life activities.¹³ However, we recognize the inherent complexity in determining what constitutes a separate symptom or condition from the underlying disability. As the Department acknowledges, the line between disabilities may sometimes be blurred, and careful consideration is needed to ensure that proposed regulations protect patients without creating undue challenges for health care providers.

The NHC offers qualified support of § 84.56(c)(1), the provision that medical professionals should have autonomy to deny treatments they deem clinically appropriate based on sound, nondiscriminatory reasons. To mitigate the potential for discriminatory judgments, the NHC emphasizes the need for medical decisions to be underpinned by current scientific understanding, comprehensive medical assessments, and an absence of prejudicial biases or overarching assumptions regarding individuals with disabilities. We propose the incorporation of targeted strategies to curtail discriminatory professional judgment, including competency-based educational modules focused on disability awareness, a structured protocol for procuring second opinions or specialized consultations, and the establishment of an independent review board — characterized by race, color, religion, sex (including pregnancy, sexual orientation, and gender identify), national origin, age, and disability diversity — that would be tasked with evaluating patient appeals related to medical treatment decisions and would be accountable for publicly disseminating the outcomes of such reviews.¹⁴

While recognizing the autonomy in professional judgment, the NHC stresses the importance of scrutiny in cases where treatment is denied. A 2019 study highlighted that physicians' biases could influence their clinical decision-making, which underscores the

¹¹ Sharby, N., Martire, K., and Iversen, M. (2015). Decreasing health disparities for people with disabilities through improved communication strategies and awareness. *International Journal of Environmental Research and Public Health*, 12(3), 3301-3316.

¹² National Institute on Minority Health and Health Disparities. (2023). *National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group on Persons Living with Disabilities: Final Progress Report September 20, 2023*. National Institute on Minority Health and Health Disparities.

¹³ Centers for Disease Control and Prevention. (2023). Disability impacts us all. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

¹⁴ National Council on Disability. (2019). Medical futility and disability bias: part of the bioethics and disability series. National Council on Disability. https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf

importance of awareness and training to mitigate such biases.¹⁵ The NHC advocates for rigorous, transparent documentation of the medical rationale in such instances to prevent discriminatory practices. The proposed guidelines rightfully emphasize that treatment decisions should be based on individualized, fact-specific inquiries, rather than generalizations. Health care professionals might encounter scenarios where a different treatment approach is warranted for a patient with disabilities, based on their unique health status. Given the complexities inherent in medical decision-making, the NHC suggests that additional examples be provided in the final rule. These should encompass a range of scenarios, reflecting both common and rare circumstances health care providers encounter.

More significantly, examples should illustrate not just clear-cut cases but also those that reside in grey areas, where the line between professional discretion and potential discrimination might blur. We believe the proposed provisions take substantial steps in this direction but also recommend continuous dialogue, education, and the use of illustrative examples to ensure these guidelines are comprehensively understood and equitably implemented in diverse health care settings.

The NHC's responses to specific questions related to medical treatment can be found beginning on page 15.

Value Assessment Methods

There has been a proliferation of value assessment methods in response to rising health care costs and a desire to allocate limited resources to areas with the highest values. The NHC believes strongly that any efforts designed to reduce health care costs must be predicated on promotion of value as defined by the patient and actively supports efforts to better incorporate patients into the ongoing debate on defining value in health care.

We commend the Department for its dedication to addressing the longstanding issue of discriminatory value assessment methods. However, many widely used methods can inadvertently marginalize individuals with disabilities, and traditional cost-effectiveness analysis often fails to capture the full benefits and costs associated with treatments for individuals with disabilities, which could lead to undervaluation of interventions that can significantly improve their quality of life.¹⁶

We urge the Department to ensure that it is considering a patient-defined definition of value, and believe that with careful consideration and stakeholder input, a balanced approach can be achieved that both promotes rigorous research and ensures the

¹⁵ FitzGerald, C. and Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC Medical Ethics*, 18(1), <https://doi.org/10.1186/s12910-017-0179-8>

¹⁶ National Minority Quality Forum. (2020). *Traditional value assessment methods fail communities of color and exacerbate health inequities white paper*. National Minority Quality Forum. <https://www.nmqf.org/s/Disparities-and-Value-Assessment-White-Paper.pdf>

equitable treatment of individuals with disabilities. By fostering an inclusive dialogue and continuously evaluating and refining value assessment methods, the Department can make significant strides toward eliminating discriminatory practices and promoting health equity for individuals with disabilities in the health care system.

The NHC's responses to specific questions related to value assessment methods can be found beginning on page 19.

Web, Mobile, and Kiosk Accessibility

The NHC commends the Department for recognizing the critical importance of ensuring robust accessibility of web, mobile, and kiosk interfaces for all individuals by creating a dedicated subpart to address the functions such technologies serve in health care. The use of these platforms for accessing health information, scheduling medical appointments, managing prescriptions, and making informed health decisions empowers individuals to take a proactive stance towards managing their health and wellbeing and facilitates a patient-centric approach with shared decision-making.^{17,18} However, this digital transformation also necessitates an equitable infrastructure that accommodates the diverse needs of all users, and it is critical to address barriers to digital inclusion.¹⁹ The NHC underscores the importance of ensuring that the proposed rule encompasses robust accessibility standards for web, mobile, and kiosk platforms to guarantee that all individuals, regardless of physical or cognitive abilities, can seamlessly access and benefit from digital health care services.

Accessible Medical Equipment

We appreciate the opportunity to provide comments on the proposed changes to Section 504 concerning the accessibility of Medical Diagnostic Equipment (MDE). We acknowledge the extensive efforts to enhance the inclusivity and accessibility of health care services for individuals with disabilities.

The NHC's responses to specific questions related to MDE can be found beginning on page 20.

Revised Provisions Addressing Discrimination and Ensuring Consistency with Statutory Changes and Significant Court Decisions

The NHC recognizes and appreciates the efforts of the Department in updating and aligning the Section 504 regulations with the current legal and social understanding of disability rights and inclusion. These changes reflect an evolved understanding and

¹⁷ Stoumpos, A., Kitsios, F., and Talias, M. (2023). Digital transformation in healthcare: technology acceptance and its applications. *International Journal of Environmental Research and Public Health*, 20(4), doi: 10.3390/ijerph20043407

¹⁸ Meskó, B., Drobni, Z., Bényei, É., Gergely, B., and Györffy, Z. (2017). Digital health is a cultural transformation of traditional healthcare. *mHealth*, 3(38), doi: 10.21037/mhealth.2017.08.07

¹⁹ Rodriguez, J., Shachar, C., and Bates, D. (2022). Digital inclusion as health care – supporting health care equity with digital-infrastructure initiatives. *The New England Journal of Medicine*, 386, 1101-1103.

respect for individuals with disabilities and emphasize the necessity of ensuring broad, nondiscriminatory access to health programs and activities funded by the federal government.

We strongly support the Department's move to update terminology used within its regulations. Replacing terms like “handicap” and “handicapped person” with “individual with a disability” and substituting more dated and stigmatized terms with “individual with a substance use disorder” and “individual with an alcohol use disorder” represents a positive and respectful change. These updates are not merely cosmetic; they are a crucial step toward reducing stigma and discrimination that individuals with disabilities face, both in health care settings and in broader society. This change also reflects the person-first language that is a current best practice in respectful and dignified communication.

Relationship to Other Laws: Revisions to Subpart A

The NHC acknowledges and supports the provision that these revisions do not invalidate or limit the remedies, rights, and procedures of any other federal laws that provide equal or greater protections for individuals with disabilities, such as the Americans with Disabilities Act (ADA). This assurance is fundamental to maintaining a comprehensive support system for individuals with disabilities, ensuring that they have the most extensive set of tools and legal avenues available to advocate for their rights. Furthermore, it underscores the principle that laws are layered, working in concert rather than in isolation, to protect individuals with disabilities.

Definition of Disability: Revisions to Subpart A

The NHC commends the inclusive approach adopted in the proposed revisions, reflecting the Americans with Disabilities Amendment Act (ADAAA)'s intentions by construing the definition of “disability” broadly and ensuring expansive coverage. This approach aligns with our advocacy for policies that recognize the full spectrum of disabilities, and it reinforces the legal protections for all individuals under this scope. The substitution of updated, respectful, and scientifically current terminology for certain conditions is a positive step forward in aligning the language of the regulation with modern understandings and perspectives.

Additionally, we support the explicit inclusion of Long COVID as a recognized condition within the list of physical and mental impairments. This timely update is crucial in acknowledging the emerging health challenges and ensures that individuals suffering from long-term effects of COVID-19 have necessary legal protections and access to support and accommodations. However, we urge clarity and caution in implementing and interpreting the definitions and examples of impairments to ensure they are indeed illustrative and non-exhaustive, as the full breadth of Long COVID manifestations is likely still not fully understood.

The NHC provides the following suggestions for improvement and clarification:

- **Clarifying Ambiguities:** While the ADAAA encourages broad interpretation, entities tasked with enforcing these regulations may face challenges in ambiguous cases. Guidance or illustrative examples of scenarios and conditions could be beneficial in aiding consistent and fair application.
- **Educational and Compliance Resources:** The NHC suggests that the Department should provide educational resources and training materials to assist in understanding these revisions. This step will ensure that organizations, health care providers, and other relevant bodies are well-equipped to comply with these regulations and understand the full scope of the protections they are required to uphold.
- **Monitoring and Reporting Mechanisms:** We recommend establishing clear, accessible channels for individuals to report non-compliance or discrimination and mechanisms for governmental monitoring of compliance. Such steps will help ensure that these robust protections are not just theoretical but actively upheld in practice.
- **Ongoing Review and Revisions:** Given the dynamic nature of health care and disability rights, we advocate for a systematic review process for these regulations, ensuring they remain relevant and responsive to societal, medical, and technological changes.

Major Life Activities

The NHC strongly supports the proposed changes in Section 84.4(c), acknowledging the significant impact of the ADAAA in broadening the understanding and scope of what constitutes major life activities. This inclusive approach is vital as it recognizes the diverse ways in which disabilities can impact individuals' lives, thus ensuring broader protection and accommodation for individuals with varying disabilities. While we are in favor of these proposed revisions, we suggest the following to enhance the application and effectiveness of these regulations further:

- **Explicit Inclusion of Mental Health:** While the understanding of major life activities has expanded, we recommend explicitly including mental health functions and cognitive abilities. This explicit inclusion would affirm the protections for individuals with mental health conditions and cognitive impairments, ensuring they receive full accommodations.
- **Guidance on Emerging Conditions:** With constant advancements in medical science, new conditions or understandings of existing conditions may emerge. We recommend establishing a systematic review process that allows for the consideration and inclusion of these emerging conditions within the framework of the law.
- **Education and Training:** To ensure the effective implementation of these expansive interpretations, it is crucial to accompany these changes with comprehensive education and training initiatives. These efforts should aim to

inform both the public and professionals about the broadened scope of what constitutes a disability and major life activities.

- **Strong Enforcement Mechanisms:** Broad definitions require robust enforcement. We suggest the strengthening of enforcement mechanisms to ensure that these inclusive definitions result in actual improved conditions and legal recourse for individuals with disabilities.

Substantially Limits

The term “substantially limits” is a critical aspect of disability law, often discussed in the context of the ADA and its amendments, defining the scope of who is considered disabled and therefore eligible for certain protections and accommodations. We appreciate the Department clarifying many aspects of this important term. In response to proposed section 84.4(d), the NHC provides the following comments:

- **Broad Interpretation of “Substantially Limits” (§ 84.4(d)(1)(i)):** The NHC strongly supports the proposal for a broad interpretation of the term “substantially limits.” We agree that a generous definition is essential to ensure that all individuals with disabilities, particularly those with conditions that fluctuate in severity, are adequately protected under the law. This broad approach encapsulates the intended spirit of inclusivity envisioned by the ADA.
- **Focus on Compliance and Discrimination (§ 84.4(d)(1)(ii)):** We commend the shift in focus towards whether entities have met their obligations and whether discrimination has occurred. This move away from extensive analysis of an individual's condition to the actions of entities should expedite the process and avoid unnecessary invasion of personal medical details, thereby respecting the dignity and privacy of individuals with disabilities.
- **Singular Substantial Limitation (§ 84.4(d)(1)(iii)):** The recognition that an impairment substantially limiting one major life activity is sufficient for disability status is crucial. It acknowledges the diverse ways disabilities can impact individuals, ensuring comprehensive protection. Furthermore, it eliminates undue burdens of proof on individuals, simplifying the process and fostering a more inclusive environment.
- **Inclusion of Episodic Impairments and Conditions in Remission (§ 84.4(d)(1)(iv)):** The explicit inclusion of episodic impairments and conditions in remission addresses a significant gap in prior interpretations. The NHC acknowledges this as a critical improvement, as it recognizes the variable nature of many health conditions, particularly chronic illnesses, and mental health conditions.
- **Comparison to the General Population (§ 84.4(d)(1)(v)):** We support the proposal that comparisons should consider the general population's condition, ensuring a realistic and empathetic assessment. However, we urge clarity in how these comparisons are drawn to avoid arbitrary or unrealistic standards.
- **Individualized Assessment and Lowered Standard of Limitation (§ 84.4(d)(1)(vi)):** The NHC agrees with the necessity for individualized

assessments. Every person experiences their health condition differently, and a standard, one-size-fits-all approach could be unjust. Requiring a lower standard of limitation than previously is a welcome change that reflects the reality of living with a disability.

- **Easing of Evidence Requirements (§ 84.4(d)(1)(vii)):** Reducing the onus on individuals to provide scientific, medical, or statistical analysis to prove their disability is a humane approach. Accepting alternative forms of evidence respects individuals' privacy and acknowledges the diverse forms of limitations experienced.
- **Disregarding Mitigating Measures (§ 84.4(d)(1)(viii)):** We fully endorse the decision to disregard the ameliorative effects of mitigating measures. This provision ensures that individuals who manage their conditions, sometimes with significant effort and/or side effects, are not penalized for doing so.
- **Coverage of "Transitory and Minor" Exceptions (§ 84.4(d)(1)(ix)):** Acknowledging that even short-term impairments can be disabling is a critical inclusion. This understanding is crucial for conditions that, while not permanent, pose significant limitations on individuals' lives.

Has a Record of Such an Impairment and Is Regarded as Having Such an Impairment

We support the in Sections 84.4(e) and 84.4(f), which offer broad protection and equal opportunities for individuals with current, past, or perceived disabilities. Section 84.4(e) commendably simplifies the proof required for "a record of" impairment, reinforcing the idea that individuals' rights should not hinge on bureaucratic technicalities or inaccessible documentation. The examples provided in the section are clear and directly underscore the necessity of non-discrimination, particularly for those who have had past health challenges or have been misclassified due to societal or institutional misunderstandings. However, we suggest further emphasizing the need for training and education among program administrators and educators to ensure this provision's effective implementation. Misclassification often stems from ignorance or misconceptions about certain health conditions, and addressing this at the root would help achieve the spirit of the proposed rule. Section 84.4(f) broadens protections in line with the original intent of the Americans with Disabilities Act Amendments Act (ADAAA), requiring objective reasoning for the "transitory and minor" exception and clarifying the need to prove discrimination under section 504. However, we recommend that clear guidelines be established on how recipients can validate that an impairment is "transitory and minor" to avoid potential abuse of this clause.

Exclusions

The NHC acknowledges the inclusion of Section 84.4(g) in the proposed regulations, reflecting statutory language from the Rehabilitation Act and consistency with the ADA. However, we wish to express significant concerns and recommend reconsiderations regarding specific exclusions, particularly in light of evolving scientific understanding and legal interpretations.

- **Exclusion of Certain Gender Identity Disorders:** In line with the Fourth Circuit's ruling in *Williams v. Kincaid*, the NHC advocates for an updated interpretation of exclusions related to gender identity disorders.²⁰ The renaming of "gender identity disorder" to "gender dysphoria" in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5) reflects a substantial shift in medical and social understanding, recognizing it as a health issue rather than a disorder. We recommend that regulations reflect current medical standards and interpretations, ensuring that individuals with gender dysphoria are not categorically denied protections. We urge the Department to consider the precedent set by *Williams v. Kincaid*, highlighting the distinction between "gender identity disorders" and "gender dysphoria" and noting the potential for gender dysphoria to result from physical impairments, thereby warranting protections under the ADA and Section 504.
- **Psychoactive Substance Use Disorders:** While we recognize the exclusion of disabilities resulting from current illegal use of drugs, the NHC stresses the importance of a clear distinction between current illegal use and individuals in recovery or those partaking in a supervised rehabilitation program. It is crucial that protections are explicit for individuals in recovery, ensuring they are not subject to discrimination and have full access to necessary resources and support.
- **Sexual Orientation:** Regarding § 84.4(b)(3)'s explicit exclusion of sexual orientation from the definition of physical or mental impairment, we acknowledge the statutory basis for this exclusion per the Rehabilitation Act and the ADA. However, we emphasize the importance of holistic support systems that recognize the intersecting identities individuals may hold. While sexual orientation itself is not a disability, individuals who identify as homosexual or bisexual and have disabilities must receive full protection and support without diminished rights or stigmatization.

Health, Welfare, and Social Services: Revisions to Subpart F

We believe that these revisions have significant implications for the health care system and, most importantly, for individuals with disabilities, including those with chronic diseases and conditions. However, while the NHC recognizes the Department's intent to streamline regulations by relocating detailed requirements for communications to a new Subpart H and understand this approach's regulatory simplification, we stress the importance of maintaining, if not strengthening, the explicit protections and guidelines concerning the provision of emergency treatment for individuals who are deaf or hard of hearing and the use of auxiliary aids. Communication barriers in health care settings, especially during emergencies, significantly jeopardize patient safety and health outcomes. We urge the Department to ensure that the new Subpart H comprehensively addresses these critical areas, with clear, actionable guidance for health care providers.

²⁰ *Williams v. Kincaid*, 45 F.4th 759 (4th Cir. 2022).

This is not only about regulatory compliance but ensuring patient-centered care that respects the rights and needs of individuals with disabilities.

Subpart G – General Requirements

Integration

The concept of “integration” in the context of disability law, as outlined in Section 504 and ADA Title II, is critical for ensuring that individuals with disabilities have the opportunity to participate fully in all aspects of community life. The term “most integrated setting” refers to environments where individuals with disabilities can interact as much as possible with people without disabilities. The commitment to upholding the “integration mandate” is a significant step forward in ensuring that individuals with disabilities can enjoy inclusive, dignified, and holistic participation in society. We particularly applaud the explicit acknowledgment of the challenges faced during the COVID-19 pandemic, which indeed exacerbated segregation and highlighted the critical need for robust community-based services. To strengthen this provision, the NHC recommends the following:

- **Application of Integration Mandate:** The NHC appreciates that the proposed § 84.76(a) highlights the broad application of the integration mandate to all programs or activities receiving Federal financial assistance, irrespective of the disability involved. This inclusive approach ensures that individuals with varying types of disabilities, not just those specifically cited in past cases like *Olmstead v. L.C.*, are entitled to integrated service delivery. It is vital that this principle be upheld across various service settings, whether residential, employment, or other community-based services, to prevent any form of segregation based on an individual's disability.
- **Prohibition of Discriminatory Actions:** In § 84.76(b), the proposal rightly interprets any form of unnecessary segregation as discrimination. The NHC underscores the need for recipients to be proactive in assessing their policies, practices, or procedures, ensuring these do not inadvertently lead to segregation. Recipients must be reminded that characterizing services as “new” does not exempt them from compliance with the integration mandate.
- **Definition of Segregated Settings:** The clarification in § 84.76(c) about what constitutes a segregated setting is crucial. It acknowledges that segregation is not limited to traditional institutional settings. However, we propose that there needs to be a clear, operational framework that recipients can use to assess whether they are inadvertently creating segregated settings, especially in cases where there might be non-apparent forms of segregation.

Civil Rights Obligations as Distinct from Medicaid Law and Regulations

The NHC acknowledges the distinct legal and operational frameworks between Medicaid statutes and regulations and the civil rights obligations under Section 504 of the Rehabilitation Act and the ADA. We recognize that HHS and the Department of

Justice (DOJ) emphasize these obligations as independent from the requirements of the Medicaid program. As a voice for patients with chronic diseases and disabilities, we wish to emphasize several critical aspects in response to the proposed rule and related inquiries.

- **Clarification of Obligations Beyond Medicaid Compliance: States**, even when compliant with Medicaid program requirements, might not be fulfilling their civil rights obligations under Section 504 and the ADA. The NHC stresses that states should review their service systems comprehensively to ensure they do not unintentionally facilitate unnecessary segregation.
- **Integration Mandate and Home and Community-Based Services (HCBS):** The proposed rule's emphasis on non-discrimination and the provision of services in the most integrated setting is commendable. However, it is crucial to address the complexities arising from capped enrollments in HCBS waiver programs. States' discretion in designing these programs, including setting eligibility requirements, must not serve as a barrier to fulfilling the integration mandate. The NHC suggests close monitoring and collaboration with states to eliminate extensive waiting lists, ensuring that individuals requiring services receive them in a timely, appropriate, and integrated manner.
- **Reinforcing Collaborations for Transition Planning:** Successful transition planning requires a collaborative approach, involving local community-based service providers, residents, and their families or representatives. The NHC encourages the Department to provide clear, detailed guidance on forming these collaborations, addressing potential obstacles, and ensuring continuity of care during transitions.
- **Education and Training:** Further, we recommend that the Department, in conjunction with relevant stakeholders, develop educational materials and training programs for recipients on their obligations under Section 504. These resources should elucidate the differences between compliance with Medicaid and adherence to civil rights laws, with practical examples and best practices.

Communications

The NHC supports the Department's focus on inclusive communication, particularly the emphasis on inclusive communication, particularly with the emphasis on using plain language for patients with cognitive, developmental, intellectual, or neurological disabilities. The NHC supports the use of plain language as a mandatory standard rather than an optional modification given its critical role in patient engagement and informed consent. We also appreciate the Department's commitment to ensuring effective communication through various means, including the use of auxiliary aids and services. However, the NHC suggests that the Department provide more detailed guidance on what constitutes "necessary" aids and services and how to implement them and consider establishing centralized resources or support systems for health care providers, particularly small entities, to assist with these requirements.

Procedures

The NHC acknowledges the Department's initiative in streamlining the procedural aspects under the redesignated Subpart K, aligning the Section 504 regulations with the procedural provisions applicable to Title VI of the Civil Rights Act of 1964. Ensuring consistency across various civil rights statutes enhances the clarity and predictability of enforcement measures, which is beneficial for recipients, beneficiaries, and regulators alike.

The NHC appreciates the commitment to conducting regular compliance reviews and the provision allowing individuals to file complaints within 180 days of alleged discrimination. These are critical components in upholding accountability. Nonetheless, we propose several enhancements to these procedures:

- **Awareness and Accessibility:** Beneficiaries and participants must be made aware of their rights, the complaint mechanisms available to them, and the 180-day timeframe in a manner that is accessible and easily understandable. This information should be available in multiple languages and accessible formats to cater to a diverse population.
- **Extension in Exceptional Circumstances:** While we understand the need for a standard timeframe for complaints, there may be extraordinary circumstances where the complainant could not reasonably have filed within the 180-day period. We suggest allowing for discretionary extensions in such cases, with clear guidelines on what constitutes an exceptional circumstance.
- **Transparency in Investigations:** There should be transparency in the investigation process, with regular updates provided to the complainant. Furthermore, upon conclusion, the findings and any actions to be taken (or a justification for the lack thereof) should be communicated clearly and promptly to the complainant.
- **Support during the Complaint Process:** The complaint process should be non-intimidating, and support should be available to those who need assistance in filing their complaints. This support includes, but is not limited to, individuals with cognitive disabilities, non-English speakers, and those who lack legal representation.
- **Proactive Compliance Reviews:** While periodic reviews are crucial, the NHC also encourages proactive, ongoing monitoring methodologies that do not rely solely on filed complaints to identify non-compliance. A more proactive approach will demonstrate the Department's commitment to civil rights and disability inclusion, even when no formal complaints have been filed.

Medical Treatment Question 1 – Articulating relevant distinctions

We recommend collaborative sessions with clinical experts, patient advocacy organizations, and individuals with disabilities; these stakeholders can offer valuable insights on real-world scenarios and the challenges faced, thereby facilitating the development of a comprehensive and clear regulatory framework. The CDC has

identified the prevalence of various disabilities in the U.S. population, and this diversity indicates the necessity of nuanced understanding in medical practice.²¹ Moreover, research emphasizes the importance of engaging with the disability community to better understand the intersectionality and the broad spectrum of disabilities.^{22,23} By fostering a collaborative environment and leveraging the expertise and experiences of a broad stakeholder base, a more accurate and meaningful articulation of the distinctions between disabilities can be achieved, which in turn can inform more effective and equitable health care policies and practices.

Medical Treatment Question 2 – Other examples of discriminatory provision of medical treatment to people with disabilities

- **Pain Management:** There are numerous reports of individuals with disabilities, particularly those with invisible disabilities such as fibromyalgia or chronic fatigue syndrome, facing skepticism and bias when seeking pain management. For example, while the CDC acknowledges that chronic pain is a significant public health concern, affecting an estimated 20.9% of U.S. adults, and 6.9% of U.S. adults experiencing high-impact chronic pain, patients with fibromyalgia experienced substantial barriers in accessing pain management services, which included skepticism from health care providers.^{24,25} This discrimination can result in under-treatment and unnecessary suffering.
- **Mental Health Services:** Persons with physical disabilities may face barriers in accessing mental health services due to providers' biases or misconceptions about their ability to benefit from such services. The National Council on Disability noted in a 2017 report that people with disabilities often face disparities in mental health care, including lack of accessibility and discrimination.²⁶

²¹ Centers for Disease Control and Prevention. (2023). Disability impacts us all. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

²² Centers for Disease Control and Prevention. (2020). Disability inclusion. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html>

²³ Valez, R., Lyon, S., Wellbeloved-Stone, C., Collins, M., Rogers, C., Cantin-Garside, K., Fortes, D., Kim, C., Desai, S., Keim-Malpass, J., and Kushalnagar, R. (2022). Engaging the disability community in informatics research: rationales and practical steps. *Journal of the American Medical Informatics Association*, 29(11), 1989-1995.

²⁴ Rikard, S., Strahan, A., Schmit, K., and Guy Jr., G. (2023). Chronic pain among adults – United States, 2019-2021. *Morbidity and Mortality Weekly Report*, 72(15), 379-385.

²⁵ Lobo, C., Pfalzgraf, A., Giannetti, V., and Kanyongo, G. (2014). Impact of invalidation and trust in physicians on health outcomes in fibromyalgia patients. *The Primary Care Companion for CNS Disorders*, 16(5), doi: 10.4088/PCC.14m01664

²⁶ National Council on Disability. (2017). *National disability report: a progress report*. National Council on Disability. https://ncd.gov/sites/default/files/NCD_A%20Progress%20Report_508.pdf

- **Rehabilitation:** Individuals with progressive disabilities might be denied certain rehabilitative treatments based on assumptions about their long-term prognosis, rather than their immediate needs and potential benefits, and individuals with progressive neurological conditions often face challenges in accessing rehabilitation services, which are critical to maintaining their functionality and quality of life.^{27,28} To address these and other discriminatory practices, it is essential to ensure that medical professionals receive training on recognizing and combating bias in their clinical decision-making. The NHC commends the proposed provision and believes it marks a significant step forward in ensuring equitable treatment for persons with disabilities in the medical setting. We stand ready to work alongside the Department in further refining these regulations and advocating for the rights and dignity of all patients.

Medical Treatment Question 3 – Balancing anti-discrimination and professional judgments

The NHC believes that the examples provided, while insightful, could benefit from expansion to encompass a broader spectrum of real-world scenarios, thereby serving as a more comprehensive guide for health care professionals. Particularly, we recommend including examples that involve:

- Complex decision-making scenarios where multiple factors, including the patient's disability, comorbid conditions, and social circumstances, interplay. According to a 2021 study, patients with multiple chronic conditions often face complex medical decisions, and their experiences with the health care system can significantly impact the outcomes.²⁹
- Rare, less straightforward cases that health care professionals may encounter, thereby highlighting the nuanced application of these provisions.
- Instances of "grey areas" in clinical decision-making, illustrating both appropriate use of discretion and scenarios where lines could be unintentionally crossed, leading to discriminatory decisions.

The NHC stresses the importance of clearly defining and communicating the criteria that constitute 'legitimate, nondiscriminatory reasons' for withholding certain medical treatments. This clarity is paramount to prevent the inadvertent perpetuation of

²⁷ Helland, C., Holmøy, T., and Gulbrandsen, P. (2015). Barriers and facilitators related to rehabilitation stays in multiple sclerosis. *International Journal of MS Care*, 17(3), 122-129.

²⁸ Fortunato, R., van der Maas, N., Biland-Thommen, U., Kaufmann, M., Sieber, C., Kamm, C., Zecca, C., Gobbi, C., Chan, A., Calabrese, P., Kesselring, J., and von Wyl, V. (2021). Physiotherapy use and access-barriers in persons with multiple sclerosis: a cross-sectional analysis. *Multiple Sclerosis and Related Disorders*, 48, <https://doi.org/10.1016/j.msard.2020.102710>

²⁹ Bierman, A., Wang, J., O'Malley, P., and Moss, D. (2021). Transforming care for people with multiple chronic conditions: Agency for Healthcare Research and Quality's research agenda. *Health Services Research*, 56(Suppl 1), 973-979.

stereotypes or subjective judgments about quality of life. It is equally vital to ensure that these criteria are grounded in up-to-date medical knowledge and reflect consensus within the professional community. To complement these regulatory guidelines, we suggest the implementation of training initiatives for health care providers. These programs should focus on:

- Enhancing awareness about disability rights and the potential for unconscious biases in medical decision-making. Research indicates that implicit biases among health care professionals can adversely affect patient care and outcomes.³⁰
- Providing tools to facilitate objective, individualized assessment methods, thereby reducing reliance on subjective or speculative judgments.
- Offering strategies for effective, empathetic communication with patients with disabilities and their caregivers, ensuring informed consent and participation in decision-making.

To ensure the ongoing relevance and applicability of these examples, the NHC recommends establishing a structured feedback mechanism. This system would allow health care professionals and people with disabilities to share insights from their experiences. Analyzing these real-world examples would facilitate the continuous refinement of guidelines and help identify areas where additional clarification may be required. We propose a collaborative approach in the development of future guidelines, engaging both disability rights advocates and authoritative bodies within the medical community. This collaboration would ensure that the examples and guidelines reflect both the lived experiences of individuals with disabilities and the practical realities of medical practice.

Medical Treatment Question 5 – Scope of the term “medical treatment”

We believe that the term “medical treatment” might be too narrow to encompass the breadth of services necessary for comprehensive care for individuals with disabilities. Health care involves not just treatments but also various supportive and ancillary services, which play a crucial role in overall patient care and outcomes. Effective health care services encompass a broad spectrum of services including primary care, specialty care, hospital care, long-term care, palliative care, behavioral health care, rehabilitative services, health promotion, disease prevention, and public health.³¹ The term “medical treatment” may inadvertently limit the scope to direct medical interventions, thus overlooking these other critical components of health care. A more inclusive term or

³⁰ FitzGerald, C. and Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC Medical Ethics*, 18(1), <https://doi.org/10.1186/s12910-017-0179-8>

³¹ World Health Organization & United Nations Children's Fund. (2020). *Operational framework for primary health care: transforming vision into action*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/337641/9789240017832-eng.pdf?sequence=1>

definition might be “health care services” or “comprehensive medical care,” which would cover both direct medical interventions and supportive health care services.

Value Assessment Methods Question 1 – Equity concerns in value assessment tools for disabilities

Value assessment tools, when improperly designed or applied, may undervalue treatments that are particularly beneficial to individuals with disabilities. These methods often rely on metrics like Quality-Adjusted Life Years (QALY) or Disability-Adjusted Life Years (DALY) that have inherent biases. For instance, if a tool discounts the value of life extension for individuals with disabilities compared to those without, it inherently suggests that extending the life of a person with a disability is of lesser importance. This biased valuation can result in reduced access to treatments and interventions that are essential to this population. The use of QALYs has been widely critiqued for potentially discriminating against individuals with disabilities by assigning lower values to their lives based on health states.^{32,33,34,35}

Furthermore, many tools fail to consider non-traditional benefits that may be of high value to individuals with disabilities, such as increased independence or improved ability to participate in community or family life. A report by the National Council on Disability highlighted that standard cost-effectiveness analyses may overlook or undervalue these types of benefits, which are crucial for the well-being and social inclusion of individuals with disabilities.³⁶

Therefore, to ensure equitable opportunities and to enhance the inclusivity and fairness of value assessment tools, it is imperative to incorporate a wide range of perspectives, especially from individuals with disabilities and their advocates, in the development and application of these methods.

Value Assessment Methods Question 2 – Unaddressed disability discrimination in value assessment

The NHC would like to emphasize that beyond the discounting of life extension, another potential area of concern is the weighting or scoring system that value assessment tools

³² Esposito, L. and Hassoun, N. (2017). Measuring health burden without discriminating against the disabled. *Journal of Public Health*, 39(3), 633-639.

³³ Rand, L. and Kesselheim, A. (2021). Controversy over using Quality-Adjusted Life-Years in cost effectiveness analyses: A systematic literature review. *Health Affairs*, 40(9).

³⁴ Schenider, P. (2022). The QALY is ableist: on the unethical implications of health states worse than dead. *Quality of Life Research*, 31(5), 1545-1552.

³⁵ Mosquera, J. (2023). QALYs, disability discrimination, and the role of adaptation in the capacity to recover: The patient-sensitive health-related quality of life account. *Cambridge Quarterly of Healthcare Ethics*, 32(2), 154-162.

³⁶ National Council on Disability. (2019). *Quality-adjusted life years and the devaluation of life with a disability*. National Council on Disability.
https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf

employ. Traditional value assessment frameworks might not adequately capture the full benefits of treatments that lead to functional improvements, especially for individuals with chronic or disabling conditions. These systems might prioritize certain outcomes that may not necessarily reflect the priorities of individuals with disabilities. For instance, an emphasis on complete cure as an ultimate positive outcome might undervalue treatments that provide significant functional improvements but stop short of a complete cure.

Furthermore, the exclusion of individuals with disabilities from the development and revision of value assessment tools can lead to biases and misrepresentations. Including diverse perspectives, especially from populations that are traditionally underrepresented, can enhance the inclusivity and accuracy of value assessment methodologies.³⁷

Addressing these concerns requires a multi-faceted approach that includes revising the methodologies employed by value assessment tools, engaging individuals with disabilities in the development and application of these tools, and incorporating a broader range of outcomes and determinants that reflect the lived experiences and preferences of individuals with disabilities. Through these measures, it may be possible to reduce or eliminate discriminatory practices in value assessment and ensure a more equitable health care landscape for all individuals, regardless of disability status.

MDE Question 1 – Scoping requirements for MDE in medical facilities

The NHC advocates for a thoughtful application of scoping requirements, recognizing the unique challenges associated with MDE, which necessitates consideration of varied medical contexts and the specific needs of individuals with disabilities. The differences in how services are delivered, the immediacy of need, and the essential role of certain equipment in diagnostic procedures necessitate flexibility and breadth in scoping requirements. We propose a tiered approach based on the prevalence of equipment use, criticality in emergency situations, and frequency of updates or replacements. This approach could ensure the most vital services are readily accessible without imposing undue strain on facilities less frequented by individuals needing specific accommodations.

MDE Question 4 – Potential burdens of proposed scoping requirements

It is paramount to consider the diverse capabilities of health care providers, especially in rural or underfunded areas. While pursuing inclusivity, requirements must account for potential financial or logistical burdens. Support in the form of federal grants, a phase-in period, or tax incentives could ameliorate these challenges, ensuring facilities can comply without compromising service quality or facing financial distress.

³⁷ Moczygemba, L., Brown, C., and Johnsrud, M. (2021). "It's time to represent": shifting the paradigm to improve the quality of inputs into value assessment frameworks. *Journal of Managed Care and Specialty Pharmacy*, 27(9-a Suppl), doi: 10.18553/jmcp.2021.27.9-a.s17

MDE Questions 5, 6, and 7 – Adequacy of accessible MDE dispersion, additional dispersion requirements for accessible MDE, and considerations and burdens of MDE dispersion rules

Full dispersion of MDE is crucial in ensuring that individuals with disabilities have comprehensive access to care. It is insufficient to only have accessible equipment in certain departments, as this limitation could delay critical diagnoses and treatments. We suggest a minimum standard for each department, specialty, or clinic, buttressed by a robust logistical network enabling rapid equipment sharing between units. A system to log and monitor equipment use could identify high-demand areas, guiding resource allocation.

- **Moving/Sharing of Accessible MDE:** We acknowledge the potential for equipment sharing to mitigate costs. However, this must not compromise immediate availability. We recommend exploring innovative solutions like mobile MDE units or a centralized tracking and ordering system for rapid equipment deployment. These strategies, coupled with staff training on equipment handling and patient transfer protocols, could streamline the sharing process.
- **Burden on Recipients:** We recognize the logistical and financial implications, particularly for smaller practices or those in resource-limited settings. Collaborative strategies, shared regional resources, or a pool of readily deployable MDE could be solutions. The key is a cooperative approach, minimizing individual facility burden while maximizing patient access.
- **Impact on Patients with Disabilities:** The emotional and physical well-being of patients is paramount. Extended wait times or having to navigate to different departments can be distressing and, in some cases, harmful. Facilities should strive for internal processes that are invisible to the patient, where the availability of accessible MDE is seamless.

MDE Question 8 – Impact of paragraph (c) on accessible MDE availability

The potential impact of paragraph (c), which stipulates that health care providers receiving federal assistance must, within two years, acquire at least one examination table and one weight scale that meet the MDE Standards for accessibility, unless they already have such equipment, is substantial for individuals with disabilities, potentially ushering in greater autonomy and dignity during medical visits through improved accessibility. This requirement underscores recipients' responsibility to ensure health care inclusivity, aligning with the NHC's advocacy for patient-centered health care. However, while the NHC recognizes potential challenges for recipients, particularly small providers, due to possible financial constraints or limited availability of compliant MDE in the market, leading to higher costs, it is important to note that accessible weight scales are generally not substantially more costly than standard scales. Additionally, providers have the option to lease or purchase refurbished equipment, mitigating cost concerns. These weight scales also do not require specialized staff training, minimizing the operational impact on health care providers. Therefore, the weight scale

requirements should not be considered unduly burdensome. However, we encourage the Department to consider the varying challenges associated with different types of accessible equipment, to ensure that the provision of high-quality care is not compromised, particularly when patients are referred to other providers due to accessibility limitations, as outlined in § 84.22(c).

MDE Question 10 – Alternative methods for accessibility without acquiring MDE

Recipients may also consider forming partnerships with nearby facilities that possess accessible MDE, establishing referral systems that do not compromise the standard of care or accessibility for the patient. Additionally, mobile MDE units could be deployed to serve multiple facilities, ensuring wider access without the need for individual establishments to incur the full costs associated with purchasing or leasing equipment.

MDE Questions 11 and 12 – Recipients' leasing practices for MDE and price differential in leasing accessible MDE

We urge the Department to conduct a comprehensive survey to understand leasing practices better. Information on the prevalence of leasing, types of equipment leased, and the financial implications of leasing versus purchasing can inform more nuanced regulations and support structures.

MDE Question 13 – Alternative methods for acquiring MDE

Beyond purchasing and leasing, recipients sometimes acquire MDE through donations, long-term borrowing, or community sharing initiatives. Information should be gathered on these practices to ensure they meet accessibility standards and do not inadvertently introduce disparities in the quality of care provided to individuals with disabilities.

MDE Question 14 – Considerations for extending standards to non-diagnostic medical equipment

The NHC strongly supports the notion of extending the technical standards set forth for MDE to certain non-diagnostic medical equipment. Individuals with disabilities encounter numerous barriers in health settings, some of which involve equipment used for treatment purposes. The principles of accessibility should be universally applied, ensuring holistic care. While the MDE Standards were developed with diagnostic equipment in mind, their underlying premise is fundamentally about accessibility, a principle equally relevant to treatment equipment. For instance, the technical requirements concerning adjustable heights, support features, room for assistive devices, and communication methods are universally applicable, ensuring safety, comfort, and effective communication during any medical procedure, diagnostic or therapeutic. However, it is crucial that this application is not a blanket policy. Each piece of non-diagnostic equipment must be considered within its context, evaluating the technical feasibility, safety implications, and utility in each specific therapeutic use case. We recommend establishing an advisory committee comprising medical professionals, accessibility experts, and representatives from the disabled community to determine the

applicability of MDE Standards on a case-by-case basis for various non-diagnostic equipment types. Certain non-diagnostic equipment plays a pivotal role in the therapeutic process, where the need for accessibility standards is glaring. These include:

- **Treatment tables and chairs:** These pieces of equipment are utilized across various specialties and often require patients to move into vulnerable positions. Incorporating standards that assist with safe transfers, support, and adjustments is key to accessibility.
- **Lifts:** These are vital for patient movement and should adhere to strict standards ensuring their safe operation, including clear controls accessible to individuals with disabilities.
- **Dialysis chairs and infusion chairs:** Given the prolonged periods patients spend in these chairs, standards ensuring comfort, adjustability, and proper support are crucial.
- **Rehabilitation equipment:** For devices used in physical therapy and rehabilitation, standards need to ensure they are adaptable and accessible, allowing individuals with disabilities to fully engage with their recovery programs.

Conversely, there may be highly specialized equipment where the application of MDE Standards may not be feasible or relevant. Such determinations should balance accessibility goals with medical necessity, safety, and technical feasibility.

MDE Question 15 – Effectiveness and costs associated with staff qualification programs

From our engagement with various stakeholders, it is evident that programs emphasizing hands-on training, regular refresher courses, and simulations of patient scenarios had the most significant impact on staff competence in operating MDE. Programs that incorporated feedback from individuals with disabilities were particularly effective as they offered real-world insights and made the training more patient-centered. While these comprehensive training programs entail costs, including program development, training delivery, and staff time, our analysis suggests that these costs are offset by several benefits. These include improved patient satisfaction, reduced equipment misuse, fewer appointment cancellations due to equipment operation barriers, and enhanced staff confidence and competence, all contributing to more efficient and effective health care delivery. However, cost management strategies are essential, especially for smaller providers. We advocate for shared resources, like centralized training programs, federal or state funding assistance, and online training modules, to mitigate individual recipient costs. Additionally, collaboration with medical equipment manufacturers for staff training could be an effective strategy.

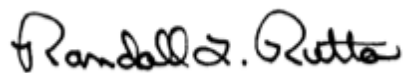
Health, Welfare, and Social Services Question 1 – Expanding beyond hospitals and outpatient facilities

The NHC strongly supports the extension of non-discrimination provisions to facilities beyond traditional hospitals and outpatient facilities. The current opioid epidemic and the broader issue of substance use disorders underscore the necessity for non-discriminatory access to a wide range of treatment programs. These should include, but not be limited to, substance use disorder rehabilitation facilities, mental health centers, primary care facilities, pain management clinics, and non-traditional providers of health-related services. Discrimination based on substance use disorder status is a barrier to recovery and integration and can further stigmatize affected individuals. Comprehensive application of non-discrimination provisions reflects the continuum of care necessary for these individuals.

Conclusion

The NHC thanks the Department for the opportunity to provide input on this important proposed rule. Please do not hesitate to contact Eric Gascho, Senior Vice President of Policy and Government Affairs, if you or your staff would like to discuss these comments in greater detail. He is reachable via e-mail at egascho@nhcouncil.org.

Sincerely,



Randall L. Rutta
Chief Executive Officer