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November 13, 2023

Honorable Xavier Becerra
Secretary
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Melanie Fontes Rainer, Director
Office for Civil Rights
Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Re: Discrimination on the Basis of Disability in Health and Human Services Programs or Activities Notice of Proposed Rulemaking (NPRM), RIN 0945-AA15

Dear Secretary Becerra and Director Fontes Rainer,

The National Health Law Program (NHeLP) is a public interest law firm that works to advance equitable access to health care and protect the health rights of people with low incomes and underserved populations. For over fifty years, we have litigated, advocated, and educated at the federal and state levels to advance health and civil rights in the United States. Consistent with our mission, we strongly believe that health care is a human right. Every individual should have access to high quality, affordable, and comprehensive health care and be able to achieve their own highest attainable standard of health.

We appreciate the opportunity to comment on and express our strong support of the Department's proposed rule, "Discrimination on the Basis of Disability in Health

and Human Services Programs or Activities.” As the first update to § 504 regulations since 1977, this proposed rule is much needed and long overdue. We urge you to finalize this rule as soon as possible, so individuals with disabilities can benefit from clarity the proposed rulemaking provides.

Below, please find comments on the Proposed Rule, with specific suggestions and comments on the text.

§ 84.2 Application

Section 504 applies to “each recipient of Federal financial assistance from the Department of Health and Human Services and to the program or activity that receives such assistance.”¹ As the Department of Health and Human Services (HHS) acknowledges, this nondiscrimination mandate in § 504 is “facially broad” and “provides no basis for excluding *some* activities in which recipients engage.”² Particularly as interpreted through the lens of § 1557 of the Affordable Care Act (ACA), § 504 prohibits discrimination not only in Medicaid, but in any health program or activity that receives federal financial assistance.³

We appreciate the acknowledgement in the § 504 NPRM preamble that the § 1557 NPRM proposes revising its interpretation of “federal financial assistance” to include Medicare. In doing so, the § 1557 NPRM makes conforming amendments to Appendix A of Part 84 of the § 504 regulations to explicitly state that § 504 applies to Medicare.⁴ For consistency, HHS should be clear in the § 504 NPRM preamble that § 504 reaches all programs or activities that receive federal financial assistance, including health insurance providers that receive federal financial assistance, such as those that run qualified health plans.⁵ The acknowledgement that § 504 reaches Medicare, but the failure to mention

¹ 45 C.F.R. § 84.2.

² See U.S. Dept. Health & Hum. Servs., *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, Notice of Proposed Rulemaking*, 88 Fed. Reg. 63392, 63403 (Sept. 14, 2023), <https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities> [hereinafter Proposed Rule].

³ See generally *U.S. v. Baylor Univ. Med. Center*, 736 F.2d 1039 (5th Cir. 1984), *cert. denied* 469 U.S. 1189 (Medicare and Medicaid constitute federal financial assistance).

⁴ Proposed Rule, at 63393.

⁵ See, e.g., *T.S. v. Heart of Cardon, LLC*, 2022 WL 3134452, 43 F.4th 737 (7th Cir. Aug. 5, 2022) (Pursuant to § 1557, a covered dependent under a self-funded health plan could sue the plan sponsor for categorically excluding coverage for autism-related services, because the sponsor accepted federal funding).



other health insurance that receives federal financial assistance, could inadvertently imply that § 504 does not reach such coverage.

§ 84.4 Disability

We support the Department’s approach to align the definition of disability for the purposes of § 504 with the language in 28 C.F.R. § 35.108 and to ensure that the definition of “disability” in each “would be construed broadly in favor of expansive coverage to the maximum extent possible.”⁶ This interpretation is consistent with Congressional intent in passing the Americans with Disabilities Act Amendments Act of 2008 (ADAAA) and judicial interpretations of both the ADAAA and § 504.⁷

We also support the addition of long COVID to the non-exhaustive list of examples of physical or mental impairments in Proposed Rule § 84.4(b)(2). Long COVID has disrupted the lives of millions of people in the last three years, and has been estimated to affect as many as 6% of the adult population.⁸ Recognizing this prevalence and the debilitating and enduring effects of long COVID by including it on this list will simplify the process for people with this condition to qualify for protection from discrimination due to their disability.

We also appreciate the Department updating the regulation to align with the Americans with Disabilities Act (ADA) regulations, recognizing that HIV infection, whether symptomatic or asymptomatic, can constitute a disability.⁹ We thank the Department for substituting “substance use disorder” for “drug addiction” and “alcohol use disorder” for “alcoholism.” These terms more accurately describe such impairments and are less stigmatizing.¹⁰

⁶ Proposed Rule, at 63459.

⁷ Americans with Disabilities Act Amendments Act of 2008, Pub. L. No. 110-325 § 2. 112 Stat. 3553 (Sept. 25, 2008) (stating the purpose of the law being to reject the narrow interpretation of disability and expand access to ADA and § 504 protection). *See, e.g., Mueck v. La Grange Acquisitions, L.P.*, 75 F.4th 469, 478-83 (5th. Cir. 2023) (distinguishing narrow interpretation of ADA definition of disability prior to the ADAAA and finding that an individual’s substance use disorder qualified as a disability under the ADAAA standard).

⁸ Nicole D. Ford et al., *Long COVID and Significant Activity Limitation Among Adults, by Age — United States, June 1–13, 2022, to June 7–19, 2023*, 72 MORBIDITY & MORTALITY WEEKLY 866 (Aug. 11, 2023), <https://www.cdc.gov/mmwr/volumes/72/wr/mm7232a3.htm>.

⁹ *See* 28 C.F.R. § 35.108.

¹⁰ Off. Nat’l Drug Control Pol’y, *Changing the Language of Addiction* (2017), <https://obamawhitehouse.archives.gov/sites/whitehouse.gov/files/images/Memo%20-%20Changing%20Federal%20Terminology%20Regrading%20Substance%20Use%20and%20Substance%20Use%20Disorders.pdf>.



We write to draw attention to two specific actions that the Department should take in the Final Rule to further ensure its regulations are consistent with this charge.

A. Recognition of Intersex Variations

The term “intersex” describes a broad range of natural variations in sex traits and anatomy.¹¹ For the reasons explained below, we believe the definition of disability enumerated in the Proposed Rule includes intersex variations, and we request that the Department add language to the rule reflecting this.

Some people with intersex variations experience “impairments” if those variations cause physical conditions that substantially limit the bodily functions of multiple organ systems, including the endocrine system, genitourinary system, and reproductive system.¹² For example, people with intersex variations affecting their reproductive system experience infertility at higher rates than people without an intersex condition.¹³ Individuals with an intersex variation known as androgen insensitivity system experience insensitivity to hormones that results in differences in development of genitals and secondary sex characteristics.¹⁴ There are also many types of intersex variations that may not limit major bodily functions of an individual, but are perceived to substantially limit reproductive or genitourinary function due to stereotypes, bias, and misinformation.¹⁵ Accordingly, a particular intersex variation may meet the definition of an impairment that

¹¹ United Nations, Off. High Comm’r, *Human Rights Violations Against Intersex People 2* (2019), <https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>; interACT Advocs. for Intersex Youth, *What is intersex? Frequently asked questions*, <https://interactadvocates.org/faq/> (last visited Nov. 1, 2023); Barbara J. King, *What Does It Mean To Be Intersex?* NAT’L PUB. RADIO (Nov. 19, 2023), <https://www.npr.org/sections/13.7/2015/11/19/456458790/what-does-it-mean-to-be-intersex>.

¹² See interACT Advocs. for Intersex Youth, *Intersex Variations Glossary* (Oct. 2022), <https://interactadvocates.org/intersex-definitions/>; Amy Rosenwohl-Mack et al., *A national study on the physical and mental health of intersex adults in the U.S.*, 15 PLOS ONE 8 (Oct. 9, 2020), <https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0240088&type=printable> (measuring prevalence of intersex variations).

¹³ Nat’l Acads. Scis., Eng’g, & Med., Comm. on Understanding Well-Being Sexual & Gender Diverse Populations, *Understanding the Well-Being of LGBTQI+ Populations* 304 (Charlotte J. Patterson, Martin-Jose Sepulveda, & Jordyn White, eds., 2020).

¹⁴ *Id.* at 372.

¹⁵ See United Nations, *supra* note 11, at 6 (discussing stigma toward intersex variations and comparison with medical and social models of disability); Nat’l Acads. Scis., Eng’g, & Med., *supra* note 13, at 370-78.



“substantially limits one or more major life activities,” or it may be “regarded as” an impairment for the purposes of § 504.¹⁶

Discrimination against people with intersex variations closely tracks the way discrimination against people with other types of disabilities is described elsewhere in the preamble and Proposed Rule. People with intersex variations often face discrimination in the form of unwanted, unnecessary, or nonconsensual medical procedures. Providers often pursue these “normalizing” procedures based on discriminatory beliefs that individuals’ bodies should conform with typical binary sex anatomy.¹⁷ The perception of intersex individuals as abnormal and the medical preference for “normalizing” surgeries, treatments, and other interventions on intersex infants and youth have had a profound effect on the physical and mental health of intersex individuals.¹⁸ Intersex individuals also report providers withholding necessary medical treatment for lack of knowledge or desire to treat a person with intersex variations. A 2022 survey of intersex adults found that more than half of respondents reported that a provider refused to treat them because of their intersex variation.¹⁹ These assumptions, stereotypes, and bias lead to medical decision-making not based in sound professional judgment but based on reasoning prohibited by § 504.²⁰

Despite the known disparities and discrimination that people with intersex variations face, people with intersex variations are rarely explicitly protected by federal

¹⁶ See interACT Advocs. for Intersex Youth, *supra* note 12; see also *Lange v. Houston Cnty.*, 608 F. Supp. 3d 1340, 1363 n.18 (M.D. Ga. 2022) (noting that physical conditions such as “‘having undescended testicles, missing ovaries, hermaphroditic conditions, genetic anomalies, or an androgen receptor disorder’ would qualify as a disability under the [ADA]”); *Inscoe v. N.C. Dep’t of Pub. Safety*, 2023 WL 307463 (W.D.N.C. Jan. 18, 2023) (determining Plaintiff had alleged ADA violations based on intersex status).

¹⁷ United Nations, *supra* note 11, at 5-7; Nat’l Acads. Scis., Eng’g, & Med., *supra* note 13, at 349 (“virtually all major medical authorities agree that...procedures to ‘normalize’ the sex characteristics of children with intersex traits who are too young to participate in consent lack evidence of benefit and show evidence of physical and mental health harms”).

¹⁸ Nat’l Acads. Scis., Eng’g, & Med., *supra* note 13, at 309.

¹⁹ Caroline Medina & Lindsay Mahowald, Ctr. Am. Progress, *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022* (Jan. 12, 2023),

<https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/>.

²⁰ See United Nations, *supra* note 11, at 13-20; Medina & Mahowald, *supra* note 19, Caroline Medina & Lindsay Mahowald, Ctr. Am. Progress, *Key Issues Facing People with Intersex Traits* (Oct. 26, 2021), <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/>.



nondiscrimination laws, even when they clearly meet the criteria for protection under the ADAAA and § 504. For these reasons, we recommend adding “intersex” to the illustrative list of physical impairments in § 84.4(b)(2).

RECOMMENDATION:

(b)(2) *Physical or mental impairment* includes, but is not limited to, contagious and noncontagious diseases and conditions such as the following: orthopedic, visual, speech, and hearing impairments, and cerebral palsy, epilepsy, muscular includes, but is not limited to, contagious and noncontagious diseases and conditions such as the following: orthopedic, visual, speech and hearing impairments, and cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, intellectual disability, emotional illness, dyslexia and other specific learning disabilities, Attention Deficit Hyperactivity Disorder, Human Immunodeficiency Virus infection (whether symptomatic or asymptomatic), tuberculosis, ***intersex variations***, substance use disorder, alcohol use disorder, and long COVID.

B. Recognition of Gender Dysphoria

We agree with the Department’s assertion that “restrictions that prevent, limit, or interfere with otherwise qualified individuals’ access to care due to their gender dysphoria, gender dysphoria diagnosis, or perception of gender dysphoria may violate § 504.”²¹ We recommend that the Department include reference to this interpretation in the text of the Final Rule to clarify that recipients must treat gender dysphoria as a disability for purposes of § 504.

Proposed Rule § 84.4(g) incorporates the ADA’s statutory exclusion of “[t]ransvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders” from the definition of “disability.” This exclusion originated from discriminatory perceptions of transgender and gender non-conforming people as morally offensive, and thus not deserving of nondiscrimination protections for any disability related to their non-normative gender.²²

²¹ Proposed Rule, at 63463-64.

²² See Ruth Colker, *Homophobia, AIDS Hysteria, and the Americans with Disabilities Act*, 8 J. GENDER, RACE, & JUST. 33 (2004) (recounting how homophobia and AIDS hysteria underpinned Congress’ decision to exclude certain groups from the ADA’s protection).



However, as the Department acknowledges, and as courts have explained, gender dysphoria differs in significant ways from Gender Identity Disorder (GID) and other disorders mentioned in the statutory exclusion.²³ The medical community used the terms GID and “transsexualism” to refer to incongruence between an individual’s sex assigned at birth and their true gender. The incongruence itself resulted in *all* transgender and gender non-conforming people qualifying for a disorder diagnosis. In contrast, gender dysphoria refers to the “stress about this incongruence” that results in clinically significant impairment in functioning.²⁴ Gender dysphoria is not necessarily experienced by all transgender and non-binary individuals, but a transgender or non-binary person may receive a diagnosis of gender dysphoria if they experience symptoms of distress and functional limitations as a result of incongruence between their sex assigned at birth and true gender. Notably, transgender, non-binary, and other gender non-conforming individuals can no longer receive a diagnosis of transsexualism or GID because the medical community has acknowledged the lack of scientific support for these diagnoses.²⁵

Because gender dysphoria clearly falls within the scope of § 504’s protection, but it is easily confused or conflated with the outdated pathologization of GID and “transsexualism,” we strongly encourage the Department to modify the language of Proposed Rule § 84.4(g) in the Final Rule to clarify the limitations of the statutory exclusion.

RECOMMENDATION: Reformat § 84.4 (g) and add a rule of construction that clarifies “gender dysphoria” falls outside of the scope of the statutory exclusions.

- (1) Exclusions. The term “disability” does not include—
 - (a) Transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders;
 - (b) Compulsive gambling, kleptomania, or pyromania; or

²³ *Williams v. Kincaid*, 45 F.4th 759, 766-68 (4th Cir. 2022) (reviewing advances in medical understanding and finding the distinction between GID and gender dysphoria is “not just semantic”).

²⁴ Am. Psychiatric Ass’n, *Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition* (DSM-V) 453 (2013).

²⁵ See Brief of LGBTQ Legal Advocates & Defenders et al. as Amici Curiae in support of Plaintiff-Appellants at 10-12, *Williams v. Kincaid*, 45 F.4th 759 (4th Cir. 2022) (No. 21-2030), <https://www.glad.org/wp-content/uploads/2021/12/20211208-Williams-v-Kincaid-amicus.pdf> (discussing evolution of scientific and medical classification of GID and gender dysphoria).

- (c) Psychoactive substance use disorders resulting from current illegal use of drugs.
- (2) ***Rule of construction. Gender dysphoria is not included in the scope of “gender identity disorders” or other conditions listed in paragraph (g)(1) of this section.***

§ 84.10 Definitions

Overall, NHeLP supports HHS’s proposal to revise the definitions in § 504 to correspond to the ADA Title II regulations, delete terminology that is obsolete, and revise certain terms to incorporate statutory changes to the Rehabilitation Act. These proposed changes will help ensure consistency of terminology between § 504 and Title II of the ADA.

A. Auxiliary Aids and Services

We support HHS’s proposal to add the definition of “auxiliary aids and services,” mirroring the definition from the ADA Title II regulations.²⁶ In our comments for the § 1557 NPRM, we suggested one modification to this definition to clarify that staff who step in to interpret for an individual with a disability must have clear qualifications to do so.²⁷ We suggest this same change here. Entities still commonly claim that external interpreting services are not necessary because they believe that current staff can provide effective communication to individuals with disabilities. We also recommend that the text clarify that “similar services and actions” are available for all individuals with disabilities, not just for deaf and hard of hearing individuals and blind and low vision individuals referenced in subsections (1) and (2).

RECOMMENDATION: Amend the definition of auxiliary aids and services to delete “and” at the end of subsection (3), add new subsection (4), and renumber subsection (4) as subsection (5) as follows:

- (4) ***Staff acting as interpreters: A recipient must not use staff who use sign language or another communication modality to act as interpreters and relay information to individuals with disabilities unless a) they meet the definition of a qualified interpreter found***

²⁶ 28 C.F.R. §§ 35.104, 36.303(b).

²⁷ Nat’l Health L. Prog., *NHeLP Comments on Section 1557 Proposed Rule 25* (Oct. 2022), <https://healthlaw.org/resource/nhelp-comments-on-section-1557-proposed-rule/>.



- within this section and b) meet the unique needs of the individual requesting the accommodation; and*
- (5) Other similar services and actions *that support individuals with disabilities in effective communication.*

B. Companion

We support HHS’s proposal to add the definition of “companion” to § 504 to be consistent with the ADA Title II regulations.²⁸ While we appreciate HHS’s explanation that a companion may include a “family member, friend, or associate of an individual...” who is “an appropriate person with whom the recipient should communicate,” we hope HHS will clarify that the determination of who is appropriate must lie with the individual with a disability (or their designated decision-maker pursuant to state law), and not with the recipient. Deferring to the individual with a disability to determine who is their companion or appropriate person to communicate with is critically important as communicating directly to non-designated companions may not only violate privacy laws, but may also undermine the autonomy of people with disabilities. As we recommended in our comments for the § 1557 NPRM, HHS should add language to this definition to clarify that the determination of who is “appropriate” lies with the individual, not with the provider.²⁹

C. Most Integrated Setting

The definition of “most integrated setting” and the standard it sets is critical to how people with disabilities experience community life. While we generally support the rationale in the preamble and the definition, we suggest changes to address ongoing issues with individuals with disabilities not being provided necessary services and supports to meaningfully access their communities.

Recipients have an affirmative duty to ensure that programs and services are designed to achieve community integration, by providing an individual the necessary supports and modifications such that they can actually be integrated with their community to the fullest extent possible. We are concerned that phrases like “opportunity” and “offers access to,” create too passive a standard as opposed to more active language that would more clearly indicate recipients’ affirmative obligation.

²⁸ 28 C.F.R. § 35.160(a)(2).

²⁹ Nat’l Health L. Prog., *supra* note 27, at 26.

NHeLP has done extensive work with community integration both through litigation and through administrative advocacy. This includes a decade of intensive advocacy to try to ensure that the Home and Community-Based Services (HCBS) Settings Rule is implemented with fidelity so that people using Medicaid HCBS receive services in a truly community-based setting.³⁰ Our work in this area has repeatedly uncovered that programs, services, and settings that merely provide “opportunities” for community integration fail to provide a person with the necessary supports to access the community or true community-based options.

The HCBS Settings Rule requires that a community-based setting be integrated in and support full access to the greater community; optimize but not regiment individual initiative, autonomy, and independence in making life choices; and uses as the comparator for community access the same degree of access to the larger community as compared to individuals who do not receive Medicaid HCBS.³¹ While we agree with HHS that the integration mandate is independent from the requirements of the Medicaid program, our experience with the HCBS Settings Rule illustrates the insufficiency of the mere “opportunity” to access the community.³² All too often, settings receiving HCBS funds include settings that provide an “opportunity” for access to the community in name only. For example, a residential setting that is “on a bus line,” where individuals can leave the residence, but under the resident’s person centered plan they need to be accompanied by staff on community outings and there is no plan or option to have staff available to accompany residents, does not provide true integration. Another example is that of a non-residential setting, such as an employment program, that provides an “opportunity” to interact with non-disabled peers because there are non-disabled peers in the factory setting, but as a practical matter, due to structural and programmatic barriers disabled and non-disabled workers rarely, if ever, interact. A mere opportunity is not enough to achieve interaction with nondisabled persons to the fullest extent possible.³³

³⁰ U.S. Dept. Health & Hum. Servs., *Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers*, 79 Fed. Reg. 2948 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441 & 447, available at <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>).

³¹ *Id.* at 3032.

³² Proposed Rule, at 63486.

³³ 28 C.F.R. pt. 35 app. B, 690 (2015); U.S. Dep’t Just., *Statement on the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (2020), https://www.ada.gov/olmstead/q&a_olmstead.htm.



The integration mandate may also be violated when individuals are isolated at home. Such isolation runs counter to the “two evident judgments” the Supreme Court identified in the integration mandate: unwarranted assumptions that persons isolated in institutions are incapable or unworthy of participating in community life; and that confinement severely diminishes the everyday life activities of individuals.³⁴ The integration mandate may be violated when a person has hours of services reduced such that they cannot participate in the community activities identified as important in their plan of care or when budgeting decisions limit a person’s ability to participate in the community.³⁵

In addition, where courts have examined what community integration looks like, there is significant focus on how a person experiences the setting and whether there are real options for interacting with community members outside of the setting. Courts have considered whether individuals are supported in interacting with non-disabled peers; have access to friends and family; have access to neighborhood amenities; and whether they have limited schedules due to lack of services.³⁶ In many cases, recipients were found to violate the integration mandate even though people had opportunities and rights on paper, were allowed to do community activities, or had technical access to the community because the facility was in the community at large, but they did not actually *experience* community integration.

An integrated setting is one that “enables individuals to interact with non-disabled persons to the fullest extent possible.”³⁷ As discussed in the preamble, there is a well-

³⁴ See, e.g., *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 462-64 (6th Cir. 2020) (discussing *Olmstead* and *Steimel*).

³⁵ *Id.*

³⁶ *Id.* at 462-64; *Steimel v. Wernert*, 923 F.3d 902, 911 (7th Cir. 2016); *Pashby v. Delia*, 709 F.3d 307 (4th Cir. 2013) (finding adult care homes institutional in nature and that the “goals often fall short of reality” of the facilities); *H.A. by L.A. v. Hochul*, 2022 WL 357213 (W.D.N.Y. 2022) (finding that engagement in community living activities misses the point that their schedules are circumscribed due to limited caregiver availability); *Murphy v. Harpstead*, 421 F. Supp. 3d 695 (D. Minn. 2019) (community integration issues found when plaintiffs showed isolation, limited choice, and lesser quality of life in group homes than independent housing); *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199 (D. Ore. 2012) (community integration of competitive work compared to facility-based or sheltered work); *DAI v. Paterson*, 598 F. Supp. 2d 289 (E.D.N.Y. 2009) (experiences of the residents showed lack of community interactions and institutional nature of the setting; cited that institutions also have community interactions so merely having community opportunities or interactions does not meet community integration).

³⁷ 38 C.F.R. pt. 35 App. A. As noted in the preamble to the Proposed Rule, the ADA and § 504 are typically read together.

recognized affirmative obligation to make benefits, services, and programs accessible.³⁸ Therefore, an integrated setting includes the affirmative duties to actually facilitate and provide access, not merely opportunities. While individuals certainly must have individual choice in activities, and the facilitation of access should never create regimented activities, a person must have a choice of integrated activities and the necessary supports and barrier removal to be able to access those activities to the fullest extent possible. Because the most integrated setting cannot simply be opportunities that do not functionally provide access, we suggest removing the more passive language from the definition.³⁹

RECOMMENDATION: Amend the definition of most integrated setting as follows:

Most integrated setting means a setting that ~~provides individuals with disabilities the opportunity to~~ **supports interaction between disabled and** with non-disabled persons to the fullest extent possible; is located in mainstream society; ~~offers~~ **provides** access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; and affords individuals choice in their daily life activities.

D. **Qualified Interpreter**

We support HHS's proposal to add the definition of "qualified interpreter" from the ADA Title II regulations to § 504.⁴⁰ However, as we recommended in our comments for the § 1557 NPRM, we suggest closer alignment for the definitions related to qualified interpreter (for an individual with a disability) and qualified interpreter for a limited English proficient individual, to ensure consistency in expectations and standards for all interpreters.⁴¹ Whether or not HHS incorporates our recommendation into the § 1557 Final Rule, we believe the definition for qualified interpreter (for an individual with a disability) should be consistent between § 504 and § 1557.

³⁸ Proposed Rule, at 63474.

³⁹ The statutory language of § 504 supports this interpretation of more active support because it includes language regarding informed choice, inclusion and full participation of individuals, and support of individual community involvement. 42 U.S.C. § 701(c). We recognize that the DOJ guidance includes language regarding opportunities and offers, but we believe that the issues experienced by individuals with disabilities in settings that purport to provide community activities but do not, and increasing problems with individuals lacking access to necessary supports for community activities, calls for stronger language that requires active provision of an integrated setting as opposed to a mere offer.

⁴⁰ 28 C.F.R. §§ 35.104, 36.104.

⁴¹ Nat'l Health L. Prog., *supra* note 27, at 27; 87 Fed. Reg. 47913.



All interpreters should demonstrate proficiency in either communicating in and understanding both English and a non-English language (including American Sign Language (ASL) or other sign languages) or proficiency in another communication modality (such as cued speech or oral transliteration). Additionally, all interpreters should interpret “without changes, omissions, or additions and while preserving the tone, sentiment, and emotional level of the original statement and [also] adhere... to generally accepted interpreter ethics principles including client confidentiality.”⁴² Alignment of these standards should decrease confusion for recipients, increase the likelihood that interpretation will meet sufficient standards and requirements, and increase the likelihood that all people who need interpretation or access to auxiliary aids and services will have the access to care they need.

RECOMMENDATION: Amend the definition of qualified interpreter as follows:

Qualified interpreter means an interpreter who, via an on-site appearance or through a video remote interpreting service (VRI):

- (1) ***has demonstrated proficiency in communicating in, and understanding:***
 - (i) ***both English and a non-English language (including American Sign Language, other sign languages); or***
 - (ii) ***another communication modality (such as cued-language transliterators or oral transliteration);***⁴³
- (2) ***is able to interpret effectively, accurately, and impartially, both receptively and expressively, using any necessary specialized vocabulary **or terms without changes, omissions, or additions and while preserving the tone, sentiment, and emotional level of the original statement; and*****
- (3) ***adheres to generally accepted interpreter ethics principles including client confidentiality.***

⁴² Nat'l Health L. Prog., *supra* note 27, at 27.

⁴³ We note that not all interpreters for people with disabilities are interpreting between English and another language. In some cases, they are acting as transliterators, interpreting from one communication modality into English. Another example would be Certified Deaf Interpreters, who are individuals who are Deaf or hard of hearing and may be interpreting between an individual who is Deaf and uses a unique version of ASL or foreign, or home signs unfamiliar to the medical interpreter (See, e.g., Registry of Interpreters for the Deaf, *Certified Deaf Interpreter Certification*, <https://rid.org/certification/available-certifications/>.)

Qualified interpreters include, for example, sign language interpreters, oral transliterators, and cued-language transliterators.

§ 84.56 Medical Treatment

A. Discrimination Prohibited

We thank the Department for ensuring that the definition of “medical treatment” in the Proposed Rule encompasses a broad and inclusive range of health care. People with disabilities too often face discriminatory denials of care that are not founded on clinically-informed, professional medical judgment and respect for disabled lives.⁴⁴ However, we are concerned that the term “medical treatment” throughout Proposed Rule § 86.56 does not fully capture the provision of all medical services and supports, particularly home and community based services such as personal care and home health services, equipment and supplies, and therapies.⁴⁵ These services and supports are a critical part of medical treatment for some people with disabilities who rely on them to live in the community with freedom of choice and access to interact with mainstream society. Recipients must be aware of their obligation to facilitate access to community-based services and supports and must be aware that failing to offer community-based options based on bias or stereotypes constitutes unlawful disability discrimination.

We therefore ask that the Department specifically add a definition of “medical treatment” similar to the definition that is included in the preamble, either in this section or in Proposed Rule § 84.10.⁴⁶

⁴⁴ See, e.g., Nat’l Council on Disability, *Framework to End Health Disparities of People with Disabilities 2* (Feb. 2022), <https://ncd.gov/sites/default/files/NCD-Framework-to-End-Health-Disparities-of-People-with-Disabilities.pdf>; Tara Lagu et al., ‘I Am Not The Doctor For You’: Physicians’ Attitudes About Caring For People With Disabilities, 41 HEALTH AFFS. 1387 (Oct. 2022), <https://doi.org/10.1377/hlthaff.2022.00475>.

⁴⁵ In other sections, the preamble of the NPRM acknowledges that people with disabilities need supportive and wraparound services in the form of paid personal care assistants, long term services and supports, dental care, SUD and OUD treatment, contraceptive care, durable medical equipment, and many more aspects of medical care and treatment that go beyond the exam room. Proposed Rule, at 63398-99 (discussing LTSS, assistive technology, and other supportive services), 63404 (discussing MOUD and life-sustaining treatment), 63411 (discussing need for supports in providing childcare), 63451 (discussing mobility supports and specialized communication for people with disabilities), 63453 (discussing need for accessible dental x-ray equipment, rehabilitation and detoxification facilities, physical therapy facilities, and more).

⁴⁶ Proposed Rule, at 63395.



RECOMMENDATION: Amend § 84.56 to add a new subsection as follows:

Definition: “Medical treatment” refers to the management and care of a patient to identify, address, treat, or ameliorate a physical or mental health condition, injury, disorder, or symptom, whether or not the condition constitutes a disability and whether the medical approach is preventive, curative, rehabilitative, or palliative. It includes the use of a wide range of regimens for both physical and mental conditions, interventions, or procedures, including surgery; the prescribing, dispensing, or management of medications; exercise; physical therapy; rehabilitation services; home health services, personal care services, the provision of equipment and supplies, and the provision of durable medical equipment.

We also urge the Department to clarify that discrimination as defined in § 84.56(a) includes not just providing or withdrawing treatment, but also offering or failing to offer a treatment. As detailed in the next several sections of this comment, people with disabilities commonly experience discrimination in the form of not being offered contraception, assisted reproductive care, abortion services, gender affirming care, and diagnostic screenings. It is also all too common for people with disabilities to be offered services that would not be offered to similarly situated people without disabilities, such as sterilization and certain types of psychiatric treatment. It should be absolutely clear from the plain language of the Final Rule that these instances also comprise discrimination in the context of § 504.

Therefore, we offer the following recommendations to modify the text of the Proposed Rule.

RECOMMENDATION: Amend § 84.56(a) as follows:

Discrimination prohibited. No qualified individual with a disability shall, on the basis of disability, be subjected to discrimination in medical treatment under any program or activity that receives Federal financial assistance, including in the allocation, ***offering***, or withdrawal of any good, benefit, or service.

B. Specific Prohibitions

We appreciate the Department’s inclusion of Proposed Rule § 84.56(b), which outlines a non-exhaustive list of examples of medical treatment discrimination that would fall within the basic requirement of § 84.56(a). We believe that the inclusion of this section will make it easier for people with disabilities to understand and exercise their legal rights, as



well as outline for recipients how disability discrimination can manifest in their medical treatment decision-making, consciously and unconsciously.

As a general comment that applies throughout the Proposed Rule, we note that the proposed text seems to use the terms “including” and “including, but not limited to” interchangeably. We read the preposition “including” as being illustrative by its nature, and therefore the phrase “but not limited to” is superfluous. However, when the phrase “but not limited to” is included in most, but not all, of the illustrative lists, it could imply a less common meaning of the word “including.” Therefore, we request that the Department either omit the phrase “but not limited to” from all illustrative lists, or use the phrase consistently throughout the regulation. In § 84.56(b), we recommend one of the approaches above to clarify that the three specific prohibitions it outlines are a *non-exhaustive* set of examples of medical treatment discrimination. While the Department’s supplementary text is clear on this point, the lack of consistency throughout the proposed regulatory text undermines this clarity.

1. Denial of medical treatment

We strongly support the Department’s inclusion of Proposed Rule § 84.56(b)(1), which makes clear that medical treatment denials or limitations that are based on bias, stereotypes, or judgments about an individual’s disability or their quality of life, are prohibited.

Numerous studies have demonstrated that health care providers hold disproportionately negative attitudes towards and inaccurate assumptions about people with disabilities.⁴⁷ Many providers have a perception that treating a patient with a disability or chronic condition differs in a “significant, meaningful, and somewhat undefined way” from patients without disabilities, reflecting a belief that it is somehow less appealing to care

⁴⁷ See, e.g., Lagu et al., *supra* note 44; Lisa I. Iezzoni et al., *Physicians’ Perceptions of People with Disability and Their Health Care*, 40 HEALTH AFFS. 297 (Feb. 2021), <https://pubmed.ncbi.nlm.nih.gov/33523739/>; Edmund Chadd & Percival Pangilinan, *Disability Attitudes in Health Care: A New Scale Instrument*, 90 AM. J. PHYSICAL MED. REHAB. 47 (Jan. 2011), <https://pubmed.ncbi.nlm.nih.gov/21169745/>; Vasiliki Matziou et al., *Attitudes of Nurse Professionals and Nursing Students Towards Children with Disabilities*, 56 INT’L NURSING REV. 456 (Dec. 2009), <https://pubmed.ncbi.nlm.nih.gov/19930074/>; Raymond C. Tervo et al., *Health Professional Student Attitudes Towards People with Disability*, 18 CLINICAL REHAB. 908 (Dec. 2004), <https://pubmed.ncbi.nlm.nih.gov/15609846/>.

for such a patient.⁴⁸ Others have expressed more explicit biases against people with disabilities, emphasizing the inconvenience and cost associated with providing the accommodations needed to properly care for such a patient.⁴⁹ Attitudinal biases can also take the form of underestimating a disabled individual's cognitive ability, desire to function independently, and interest in taking an active role in their own care.⁵⁰ Further, stereotypical beliefs can cause providers to ignore legitimate health concerns voiced by patients, particularly when they have a history of a mental health or substance use disorder.⁵¹

Research has also demonstrated that health care providers' assumptions about quality of life with a disability significantly differ from lived experience.⁵² For example, in one study, emergency care providers were asked to imagine their life after acquiring a spinal cord injury. Only 18% of physicians, nurses, and technicians responded that they would be glad to be alive after such an injury. This is in stark contrast to the 92% of actual spinal cord injury survivors who not only report being glad to be alive, but also report a high quality of life.⁵³ This study, along with the many others cited by the Department, demonstrate a serious disconnect between providers and the disabled patients they serve.⁵⁴ Most people with disabilities report an excellent or good quality of life, especially when they have access to the health care services and supports they need to maintain

⁴⁸ Nat'l Acads. Scis., Eng'g & Med., *People Living with Disabilities: Health Equity, Health Disparities, and Health Literacy: Proceedings of a Workshop* 7 (2018), <https://doi.org/10.17226/24741>; Chadd & Pangilinan, *supra* note 47.

⁴⁹ Lagu et al., *supra* note 44, at 8.

⁵⁰ Nat'l Acads. Scis., Eng'g & Med., *supra* note 48, at 7.

⁵¹ Silvia Yee et al., Nat'l Acads. Scis., Eng'g, & Med., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity* 40 (2017), <https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf>; C. Ross & E. Goldner, *Stigma, Negative Attitudes and Discrimination Towards Mental Illness within the Nursing Profession: A Review of the Literature*, 16 J. PSYCHIATRIC & MENTAL HEALTH NURSING 558 (Aug. 2009), <https://pubmed.ncbi.nlm.nih.gov/19594679/>.

⁵² See, e.g., Iezzoni et al., *supra* note 47; Nat'l Council on Disability, *Medical Futility and Disability Bias* 29 (Nov. 2019), https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf [hereinafter *Medical Futility Report*].

⁵³ Nat'l Council on Disability, *Medical Futility Report*, *supra* note 52, at 29 (citing Kenneth Gerhart et al., *Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS EMERGENCY MED. 807 (Apr. 1994), <https://pubmed.ncbi.nlm.nih.gov/8161051/>).

⁵⁴ Proposed Rule, at 63395–96.



their functioning and live full lives in their communities.⁵⁵ The pervasive undervaluation of the lives of people with disabilities can and does lead to the withholding, denial, and limitation of access to critical medical treatment.

We appreciate and agree with the Department’s analysis of the significant discrimination that people with disabilities face in accessing life-sustaining care; organ transplantation; health care when there are limited resources due to a crisis or emergency (e.g., during the COVID-19 public health emergency); and in participation in clinical research and other experimental treatments.⁵⁶ In addition to these examples, disability bias and stereotypes, judgments that an individual will be a burden on others due to their disability, and assumptions about quality of life with a disability are significantly harmful in the following contexts:

Medical Diagnostics. When an individual with a disability seeks care for a clinical concern, their disability can “overshadow” the reason for the health care visit.⁵⁷ Health care providers often lack the expertise, training, and disability competency to be able to distinguish concerns arising from an individual’s disability from those related to other health conditions.⁵⁸ Diagnostic overshadowing is particularly prevalent among people seeking health care who have intellectual or developmental disabilities, learning disabilities, and mental health disorders.⁵⁹ Too often, a provider will discredit medical

⁵⁵ See Iezzoni et al., *supra* note 47; Nat’l Council on Disability, Medical Futility Report, *supra* note 52, at 29.

⁵⁶ Proposed Rule, at 63397–401; see also Nat’l Council on Disability, Medical Futility Report, *supra* note 52; Nat’l Council on Disability, *Organ Transplant Discrimination Against People with Disabilities* (Sept. 2019), https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf [hereinafter Organ Transplant Report]; Nat’l Council on Disability, *The Impact of COVID-19 on People with Disabilities* (Oct. 2021), https://ncd.gov/sites/default/files/NCD_COVID-19_Progress_Report_508.pdf [hereinafter COVID-19 Report]; Ari Ne’eman et al., *Identifying and Exploring Bias in Public Opinion on Scarce Resource Allocation During The COVID-19 Pandemic*, 41 HEALTH AFFS. 1513 (Oct. 2022), <https://doi.org/10.1377/hlthaff.2022.00504>; Ilhom Akobirshoev et al., *Delayed Medical Care and Unmet Care Needs Due to the COVID-19 Pandemic Among Adults with Disabilities in the US*, 41 HEALTH AFFS. 1505 (Oct. 2022), <https://doi.org/10.1377/hlthaff.2022.00509>.

⁵⁷ Yee et al., *supra* note 51, at 44; The Joint Comm’n, *Diagnostic Overshadowing Among Groups Experiencing Health Disparities*, 65 SENTINEL EVENT ALERT (Jun. 22, 2022), <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf>.

⁵⁸ See, e.g., Tom Shakespeare et al., *Disability and the Training of Health Professionals*, 374 LANCET 1815 (Nov. 2009), <https://pubmed.ncbi.nlm.nih.gov/19957403/>.

⁵⁹ See, e.g., Ann Hallyburton, *Diagnostic Overshadowing: An Evolutionary Concept Analysis on the Misattribution of Physical Symptoms to Pre-existing Psychological Illnesses*, 31 INT’L J.



symptoms that an individual with a disability reports, instead assuming (based on biases and stereotypes about disability) that the individual seeking care either lacks the ability to accurately self-report, is exaggerating their symptoms, or has ulterior motives (e.g., seeking medication for a non-prescribed use). Medical diagnoses that result from or are ignored by a health care provider because of their biases about disability should fall within the purview of Proposed Rule § 84.56(b)(1). As HHS notes, denials of care that are based on biases about disabilities can violate both § 84.56(b)(1) and § 84.56(b)(2).

Abortions and Related Care. The proposed regulatory text at § 84.56(b)(1) will help fight abortion denials on the basis of bias or stereotypes related to an individual’s disability. Abortion barriers are especially dangerous for people with disabilities, who have an eleven times greater risk of maternal mortality and three times greater risk of experiencing sexual assault than their non-disabled counterparts.⁶⁰ Disabled people have long faced disproportionate abortion barriers.⁶¹ Following the U.S. Supreme Court’s decision to overturn the constitutional right to abortion in *Dobbs v. Jackson Women’s Health Organization*, abortion barriers have only increased.⁶² Because of pervasive ableism and resulting biases and stereotypes, many providers do not view people with disabilities, and especially those with intellectual and developmental disabilities, as

MENTAL HEALTH NURSING 1360 (Dec. 2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9796883/pdf/INM-31-1360.pdf>; Amir Javaid, *Diagnostic Overshadowing in Learning Disability: Think Beyond Disability*, 23 PROGRESS NEUROLOGY & PSYCHIATRY 8–10 (2019), <https://doi.org/10.1002/pnp.531>; Simon Jones et al., *Diagnostic Overshadowing: Worse Physical Health Care for People with Mental Illness*, 118 ACTA PSYCHIATRICA SCANDINAVICA 169 (Sept. 2008), <https://pubmed.ncbi.nlm.nih.gov/18699951/>.

⁶⁰ Nat’l Insts. Health, *NIH Study Suggests Women with Disabilities Have Higher Risk of Birth Complications and Death* (Dec. 15, 2021), <https://www.nih.gov/news-events/news-releases/nih-study-suggests-women-disabilities-have-higher-risk-birth-complications-death>; Shruti Rajkumar, *With Roe v. Wade Overturned, Disabled People Reflect on How it Will Impact Them*, NAT’L PUB. RADIO (Jun. 25, 2022), <https://www.npr.org/2022/06/25/1107151162/abortion-roe-v-wade-overturned-disabled-people-reflect-how-it-will-impact-them>.

⁶¹ For example, since 1980, the Hyde amendment—an annual appropriations rider that severely restricts federal abortion funding—has operated as a de-facto abortion ban for approximately one in four Medicaid enrollees, many of whom are disabled. Madeline T. Morcelle, Nat’l Health L. Prog., *Fostering Equitable Access to Abortion Coverage: Reversing the Hyde Amendment* (Mar. 25, 2021), <https://healthlaw.org/resource/fostering-equitable-access-to-abortion-coverage-reversing-the-hyde-amendment/>.

⁶² *Dobbs v. Jackson Women’s Health Organization*, 597 U.S. ___, 142 S. Ct. 2228 (2022).; Jamie Ducharme, *For People With Disabilities, Losing Abortion Access Can Be a Matter of Life or Death*, TIME (Jan. 25, 2023), <https://time.com/6248104/abortion-access-people-with-disabilities/>.



“competent” to decide whether to continue their pregnancies or have an abortion, resulting in prohibited denials of care.⁶³

Post-Roe Access to Care for Chronic Conditions. Beyond abortion, the Supreme Court’s decision in *Dobbs* has undermined or threatened access to critical teratogenic (*i.e.*, capable of harming a pregnancy), abortifacient (*i.e.*, capable of ending a pregnancy), and contraceptive (*i.e.*, capable of preventing a pregnancy) medications that help manage chronic health conditions, such as rheumatoid arthritis, lupus, cluster headaches, endometriosis, and Ehlers-Danlos Syndrome. Some pharmacies within and beyond abortion ban states have refused to fill prescriptions or are requiring that people navigate onerous red tape before they can access their medications.⁶⁴ Some providers have refused to prescribe or refill medications that can end or cause complications to hypothetical pregnancies.⁶⁵ Some health insurance companies are refusing to cover essential medications for chronic health conditions.⁶⁶ As HHS has recognized in the context of post-*Roe* pharmacy denials, these denials of medical treatment for chronic

⁶³ Nat’l P’ship for Women & Fams. & Autistic Self Advoc. Network, *Access, Autonomy, and Dignity: Abortion Care for People with Disabilities* 12–13 (Sept. 2021), <https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-abortion.pdf>; Marissa Ditkowsky, Nat’l P’ship for Women & Fams., *Disabled People Face Renewed Threats to Autonomy after Dobbs Decision* (Jul. 18, 2023), <https://nationalpartnership.org/disabled-people-face-renewed-threats-to-autonomy-after-dobbs-decision/>.

⁶⁴ See, e.g., Rose Horowitch, *State Abortion Bans Prevent Women from Getting Essential Medication*, REUTERS (Jul. 14, 2022), <https://www.reuters.com/world/us/state-abortion-bans-prevent-women-getting-essential-medication-2022-07-14/>; Bethany Dawson, *Woman Describes How She Was Humiliated at a Walgreens as Autoimmune Patients Become Collateral Damage in the U.S. Abortion Crackdown*, BUSINESS INSIDER (Jul. 31, 2022), <https://www.businessinsider.com/roe-v-wade-autoimmune-patients-collateral-damage-of-abortion-ban-2022-7>.

⁶⁵ See, e.g., Rebecca Flood, *Anger as Woman Denied 'Abortifacient' Medication After Roe v. Wade Ruling*, NEWSWEEK (Jul. 4, 2022), <https://www.newsweek.com/anger-woman-denied-abortifacient-medication-roe-v-wade-abortion-1721428>; Liz Plank, *Abortion Bans are Stopping These Women from Getting Medication for their Chronic Illness*, MSNBC (Jul. 11, 2022), <https://www.msnbc.com/opinion/msnbc-opinion/post-roe-abortions-aren-t-only-healthcare-being-denied-women-n1296928>; Ellen Matloff, *One Year After Dobbs Decision, Women Blocked from Meds for Conditions Unrelated to Abortion*, FORBES (Jun. 23, 2023), <https://www.forbes.com/sites/ellenmatloff/2023/06/23/one-year-after-dobbs-decision-women-blocked-from-meds-for-conditions-unrelated-to-abortion/?sh=72160d7b3277>; Kylie Cheung, *Woman with Severe Chronic Pain Was Denied Medication for Being ‘Childbearing Age*, JEZEBEL (Sept. 22, 2022), <https://jezebel.com/woman-with-severe-chronic-pain-was-denied-medication-fo-1849569187>.

⁶⁶ See Plank, *supra* note 65.



illnesses just because the treatments can have an alternative reproductive-related use can constitute violations of § 504.⁶⁷

Contraceptive Care. Providers routinely do not offer people with disabilities comprehensive and non-coercive contraceptive counseling and care, fail to provide sufficient and complete information about available contraceptive options, or minimize or deny contraception requests by disabled people.⁶⁸ These denials of and limitations on medical treatment and services generally result from providers' discriminatory biases and stereotypes about people with disabilities' sexual activity (e.g., believing that people with disabilities are asexual or hypersexual).⁶⁹ This discrimination is exacerbated for BIPOC, LGBTQI+ people, and immigrants with disabilities, who are burdened with the compounding effects of intersectional discrimination.⁷⁰

⁶⁷ See, e.g., U.S. Dep't Health & Hum. Servs., *Guidance to Nation's Retail Pharmacies: Obligations Under Federal Civil Rights Laws to Ensure Nondiscriminatory Access to Health Care at Pharmacies* (Revised Sept. 29, 2023), <https://www.hhs.gov/civil-rights/for-individuals/special-topics/reproductive-healthcare/pharmacies-guidance/index.html>.

⁶⁸ The National Health Law Program recognizes that barriers to sexual and reproductive health care access affect people of all gender identities. Accordingly, we use gender-inclusive language in our analysis except when we are referencing data and research that focus on cisgender women or when "women" are included in a statutory or regulatory term. More inclusive research and policy terminology are needed. Nat'l P'ship for Women & Fams. & Autistic Self Advoc. Network, *Access, Autonomy, and Dignity: Contraception for People with Disabilities* 13 (Sept. 2021), <https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-contraception.pdf>.

⁶⁹ *Id.*; William Mosher et al., *Disparities in Receipt of Family Planning Services by Disability Status: New Estimates from the National Survey of Family Growth*, 10 *DISABILITY HEALTH J.* 394 (2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5477975/>; Laura H. Taouk et al., *Provision of Reproductive Healthcare to Women with Disabilities: A Survey of Obstetrician-Gynecologists' Training, Practices, and Perceived Barriers*, 2 *HEALTH EQUITY* 207 (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6110183/>; Mary Lou Breslin et al., Nat'l Council on Disability, *The Current State of Health Care for People with Disabilities* (2009), <https://www.ncd.gov/publications/2009/Sept302009>.

⁷⁰ Shane Lamba et al., *Self-Reported Barriers to Care Among Sexual and Gender Minority People with Disabilities: Findings from the PRIDE Study, 2019-2020*, 113 *AM. J. PUB. HEALTH* 1009 (2023), <https://ajph.aphapublications.org/doi/10.2105/AJPH.2023.307333>; Megan Buckles & Mia Ives-Ruble, *Ctr. Am. Progress, Improving Health Outcomes for Black Women and Girls with Disabilities* (Feb. 2022), <https://www.americanprogress.org/article/improving-health-outcomes-for-black-women-and-girls-with-disabilities/>; Nat'l Women's L. Ctr., *Immigrant Rights and Reproductive Justice: How Harsh Immigration Policies Harm Immigrant Health* (Apr. 2017), <https://nwlc.org/wp-content/uploads/2017/04/Immigrant-Rights-and-Reproductive-Justice.pdf>; see Nat'l P'ship for Women & Fams. & Autistic Self Advoc. Network, *supra* note 63.

Assisted Reproduction. Far too often, recipients deny or limit access to assisted reproductive technology (ART), such as fertility preservation and in vitro fertilization, for people with disabilities. Discriminatory assumptions about parenting ability or eugenic fears that children will also be disabled may underpin providers' decisions to not refer patients to fertility therapy.⁷¹ These denials can also be based on discriminatory beliefs that if a person with disabilities has children, they or their children will become a burden on society.⁷² Such denials are prohibited under Proposed Rule § 84.56(b)(1). We encourage HHS to include reference to discrimination in ART treatment in the preamble as an example of prohibited conduct in the preamble to the Final Rule.

Gender Affirming Care. Transgender and non-binary individuals with disabilities face compounding discrimination that multiplies barriers to health care access, and especially access to gender affirming care. LGBTQI+ people with disabilities generally experience higher rates of discrimination and bias from providers than do all LGBTQI+ individuals and non-LGBTQI+ individuals.⁷³ Discrimination against disabled transgender and non-binary individuals seeking access to gender affirming care often manifests in discriminatory medical treatment decisions that would be prohibited under Proposed Rule § 84.56(b)(1). For example, a provider may assume that an individual with autism is incapable of making an autonomous decision about their gender identity.⁷⁴ Thus, they may limit an individual's access to gender affirming care on the basis of bias or stereotypes about autism, rather than on sound medical judgment.⁷⁵ Transgender and non-binary individuals also experience specific barriers resulting from bias or stereotypes about gender dysphoria. A 2022 survey of LGBTQI+ individuals found that one in four transgender and non-binary individuals encountered a provider who refused to document

⁷¹ Anita Silvers et al., *Reproductive Rights and Access to Reproductive Services for Women with Disabilities*, 17(4) AMA J. ETHICS 433 (Apr. 2016), <https://journalofethics.ama-assn.org/article/reproductive-rights-and-access-reproductive-services-women-disabilities/2016-04>.

⁷² *Id.*

⁷³ Medina & Mahowald, *supra* note 19.

⁷⁴ This bias is further discussed in connection to anti-LGBTQI+ state actions in Consortium for Constituents with Disabilities, *Consortium for Constituents with Disabilities Members Denounce Attacks on LGBTQI+ Rights, Call for Comprehensive Non-Discrimination, Care and Accessibility Measures* (Jul. 19, 2023), <https://dredf.org/2023/07/19/ccd-trans-lgbtqi-rights-statement/>.

⁷⁵ This discrimination would also be prohibited under Proposed Rule § 84.56(b)(2) on the basis of a person with a disability seeking treatment for a separately diagnosable condition. For example, a provider that denies access to gender affirming care to a person with autism—but would not deny the same care to a person without autism—violates Proposed Rule § 84.56(b)(2).

symptoms of or treat gender dysphoria.⁷⁶ We encourage HHS to clarify in the preamble to the rule that refusal to treat gender dysphoria and efforts to actively block access to gender affirming care for disabled patients constitute discrimination within the meaning of Proposed Rule § 84.56(b)(1) and § 84.56(b)(2).

Medical Treatment Denials Resulting from Automated Decision-Making. Evidence increasingly shows that clinical algorithms and other forms of automated decision-making, including machine learning, can reflect or amplify biases embedded in the underlying data used to develop them. Biases have been documented in everything from data collection to research methodologies, diagnostic tools, and accessing health care.⁷⁷ Common health care data sources (e.g., claims data, Medicaid expenditures data, etc.) often reflect historical biases in treatment access.⁷⁸ Health care has historically been a system of austerity—providing only certain amounts of services limited by a variety of factors including availability, ability to pay, or policies that dictate what would be provided in a particular treatment setting at that point in time for the population or person in question. Automated decision-making systems can incorporate and replicate reduced access to health care based on historical biases in the data, including biases against people with disabilities.⁷⁹ For example, the Medicaid HCBS system, which provides alternatives to institutional placements, has long lacked sufficient funding, favored congregate rather than independent settings, and relied on family caregivers to provide unpaid supports and services. This underfunding stems partly from paternalistic policies that discounted the value of supports to promote autonomy and integration for people with disabilities. Automated allocation tools that rely on historical HCBS claims data without making adjustments to correct for underfunding or changes in the law, including community integration and banning compulsion of natural supports in certain HCBS programs, will likely identify insufficient resources or recommend insufficient services to meet someone’s actual needs. There have also been examples of eligibility and allocation tools for HCBS that discriminate against people with certain diagnoses,

⁷⁶ Medina & Mahowald, *supra* note 19.

⁷⁷ See, e.g., Hannah E. Knight et al., *Challenging Racism in the Use of Health Data*, 3 LANCET E144 (Mar. 1, 2021) (explaining how structural inequalities, biases, and racism in society are easily encoded in datasets and application of data science and how it can reinforce existing injustices and inequalities).

⁷⁸ Ziad Obermeyer, *Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations*, 366 SCIENCE 447 (Oct. 25, 2019), <https://science.sciencemag.org/content/366/6464/447>.

⁷⁹ See generally Elizabeth Edwards & David Machledt, Nat’l Health L. Prog., *Principles for Fairer, More Responsive Automated Decision-Making Systems* (May 2023), <https://healthlaw.org/resource/principles-for-fairer-more-responsive-automated-decision-making-systems/>.

including cognitive diagnoses.⁸⁰ HHS should consider the potential structural biases in clinical algorithms and automated decision-making systems as a source of discrimination against people with disabilities that would fall within the meaning of Proposed Rule § 84.56(b)(1).

While we commend the Department’s inclusion of § 84.56(b)(1), we offer a few amendments in order to fully effectuate this section’s nondiscrimination objective. First, under subsection (b)(1)(iii), we recommend adding that medical treatment denials or limitations can also not be based on “assumptions about a person with a disability’s quality of life.” As detailed above and in the preamble to the Proposed Rule, a large proportion of health care providers have extremely inaccurate and negative perceptions about the quality of life of people with disabilities.⁸¹ While we recognize that the Department’s current proposed text expresses a similar concept, we believe that the terminology “quality of life” is more commonly used by health care providers and will frame the concept in a manner that will be more readily understandable to them. For example, one may be hard pressed to find a health care provider who will openly assert that “the life of a person with a disability has lesser value than the life of a person without a disability.” Yet, when asked whether they believe a person with a disability has a lower quality of life than a person without a disability, a vast majority would likely respond in the affirmative. Likewise, the last phrase of proposed subsection (b)(1)(iii) (“A belief . . . that life with a disability is not worth living”) does not fully capture the concept of assumptions about quality of life. It captures the extreme—that an individual has or will have zero (or less than zero) quality of life—but it does not reach situations where a provider assumes that a disabled person has or will have a *low* (but, non-zero) quality of life. For these reasons, we recommend explicitly including “assumptions about a person with a disability’s quality of life” as a discriminatory consideration for medical treatment decision-making.

Additionally, the terms “patient,” “individual,” and “person” are used interchangeably in this subsection. We recommend consistency in the Final Rule and favor terms that acknowledge people with disabilities as a whole person and not just a patient. For these reasons, we recommend changing the term “patient” to “individual” in subsection (b)(1)(i).

⁸⁰ See, e.g., Benefits Tech Advoc. Hub, *Case Study Library: Arkansas Medicaid HCBS Hour Cuts, Missouri HCBS eligibility cuts, and Wisconsin Medicaid HCBS Terminations*, <https://www.btah.org/case-studies.html> (last visited Nov. 3, 2023).

⁸¹ See Proposed Rule, at 63395–96.

RECOMMENDATION: Amend § 84.56(b)(1) as follows:

- (1) *Denial of medical treatment.* A recipient may not deny or limit medical treatment to a qualified individual with a disability when the denial is based on:
 - (i) Bias or stereotypes about *an individual's* patient's disability;
 - (ii) Judgments that the individual will be a burden on others due to their disability, including, but not limited to caregivers, family, or society; or
 - (iii) ***Assumptions about a person with a disability's quality of life, a belief that the life of a person with a disability has lesser value than the life of a person without a disability, or a belief that life with a disability is not worth living.***

2. Denial of treatment for a separate symptom or condition

We support the Department's inclusion of Proposed Rule § 84.56(b)(2), which makes clear that when a person with a disability seeks treatment for a separately diagnosable symptom or condition, then a provider may not deny or limit treatment if it would be offered to a similarly situated person without a disability.

It is our understanding that the terminology "deny or limit" in § 84.56(b)(2) and (b)(1) is to be interpreted broadly. For example, this language should encompass situations where a provider withholds, does not offer, or does not consider offering medical treatment or information about medical treatment to a person with a disability, when they would do so with a similarly situated non-disabled individual. In other words, when a provider's implicit biases about disability cause them to fail to offer clinically appropriate treatment options or information, such an action or inaction should fall within the purview of Proposed Rule § 84.56(b)(2). Because of the pervasiveness of implicit bias about disability in the health care system, we think it is important for the Department to clarify and emphasize the broad scope of circumstances that operate as denials and/or limitations of medical treatment in the preamble to the Final Rule.

Proposed Rule § 84.56(b)(2) serves as an important recognition that disabled individuals are entitled to the same level and types of care as anyone else—without value judgments or misguided assumptions about quality of life. In particular, we agree with and appreciate the Department's analysis of the pervasive discrimination that people with disabilities face when trying to access organ transplantation, treatment for COVID-

19, or other care when there are limited resources due to a public health emergency.⁸² Additionally, we highlight two additional examples of how this provision will strengthen safeguards for the health care rights of people with disabilities:

Care for Conditions or Symptoms Separate from HIV. Due to stigma and discrimination, people living with HIV are often denied care. These are often denials of treatment or services for symptoms or conditions separate from their HIV status. For example, in 2021, Comfort Hands, a home health provider based in Marlton, New Jersey denied care to a 59-year-old woman because she had HIV.⁸³ The woman sought home health services because she is unable to walk and needs assistance to leave her bed due to a separate condition from HIV.

Preventive Screenings for Sexually Transmitted Infections (STI) and Reproductive Cancers. People with disabilities are significantly less likely to receive high-value preventive services such as Pap tests and mammograms, which are necessary to screen for or assess symptoms related to separate STIs or reproductive cancers (e.g., cervical, endometrial, or other gynecological cancers, or breast cancer).⁸⁴ While some of these inequities may be attributed to a lack of accessible medical diagnostic equipment (as discussed below), there is also evidence that providers are less likely to offer disabled individuals these screening services.⁸⁵ This is often due to assumptions regarding the sexual and reproductive health needs, sexual activity, decision-making and

⁸² Proposed Rule, at 63400–01, 63405; see also Nat'l Council on Disability, Organ Transplant Report, *supra* note 56; Nat'l Council on Disability, COVID-19 Report, *supra* note 56; Ne'eman et al., *supra* note 56; Akobirshoev et al., *supra* note 56.

⁸³ Josh Bakan, *Woman with HIV Denied Care By Burlington Co. Home-Health Services: Feds, PATCH* (Aug. 30, 2023), <https://patch.com/new-jersey/moorestown/woman-hiv-denied-care-burlington-co-home-health-service-feds>.

⁸⁴ For purposes of our comments on this proposed subsection, we are referring to situations in which an individual with a separate disability (e.g., physical, intellectual, developmental, or other disability) is denied Pap tests, mammograms, or other preventive screenings for STIs and gynecological cancers. However, we recognize that these conditions are in and of themselves disabilities and would be covered under Proposed Rule § 84.4(b)(ii)(2). See, e.g., Lisa Iezzoni et al., *Associations Between Disability and Breast or Cervical Cancers, Accounting for Screening Disparities*, 59 MED. CARE 139 (Feb. 2021), <https://pubmed.ncbi.nlm.nih.gov/33201087/>; Brian Armour et al., *State-Level Differences in Breast and Cervical Cancer Screenings by Disability Status*, 19 WOMEN'S HEALTH ISSUES 406 (Aug. 2009), <https://pubmed.ncbi.nlm.nih.gov/19879454/>.

⁸⁵ See, e.g., C. Brooke Steel et al., *Prevalence of Cancer Screening Among Adults with Disabilities*, 14 PREVENTING CHRONIC DISEASES 1 (Jan. 2017), <http://dx.doi.org/10.5888/pcd14.160312>.



parenting abilities, and risks of people with disabilities.⁸⁶ Withholding these screenings from people with disabilities constitutes a prohibited limitation on or denial of care and contributes to significantly higher rates of breast cancer (3.55% v. 2.2%) and cervical cancer (0.9% v. 0.6%) among people with disabilities compared to people without disabilities.⁸⁷

For disabled people of color, disability-based denials and limitations on preventive screenings compound racial inequities in access to care. For example, denials of and limitations on screening for mammograms are especially dangerous for Black women, who have a 40% higher breast cancer mortality rate than white women, and Indigenous women, who are 17% less likely to be diagnosed with breast cancer than non-Hispanic white women but 4% more likely to die from the condition.⁸⁸ Compared with white people, overall STI rates are 5–8 times higher for Black people, 3–5 times higher for Native American Indian or Alaska Native and Native Hawaiian and Other Pacific Islander People, and up to 2 times higher for Hispanic people.⁸⁹ Black women are 30% more likely to develop and 60% more likely to die from cervical cancer, and nearly twice as likely to die from endometrial cancer, than non-Hispanic white women.⁹⁰ Disability-based denials and limitations on access to preventive care compound these racial inequities.

3. Provision of medical treatment

We strongly support the Department's Proposed Rule § 84.56(b)(3), which would prohibit the discriminatory provision of medical treatment to individuals with disabilities. We are grateful that HHS has recognized the discriminatory forced and coercive sterilization of

⁸⁶ See, e.g., Kenneth Robey et al., *Implicit Infantilizing Attitudes About Disability*, 18 J. DEVELOPMENTAL & PHYSICAL DISABILITIES 441 (Sept. 2006), <https://doi.org/10.1007/s10882-006-9027-3>; Maureen Milligan & Aldred Neufeldt, *The Myth of Asexuality: A Survey of Social and Empirical Evidence*, 19 SEXUALITY & DISABILITY 91 (Jun. 2001), <https://doi.org/10.1023/A:1010621705591>.

⁸⁷ Iezzoni et al., *supra* note 84.

⁸⁸ Sandy McDowell, Am. Cancer Soc'y, *Breast Cancer Death Rates are Highest for Black Women—Again* (Oct. 3, 2022), <https://www.cancer.org/research/acs-research-news/breast-cancer-death-rates-are-highest-for-black-women-again.html>

⁸⁹ Med. Inst. for Sexual Health, *Racial/Ethnic Disparities and STIs*, <https://www.medinstitute.org/racial-ethnic-disparities-and-stis/> (last visited Nov. 3, 2023).

⁹⁰ Jennifer Spencer et al., *Racial and Ethnic Disparities in Cervical Cancer Screening From Three U.S. Healthcare Settings*, 65(4) AM. J. PREVENTIVE MED. 677 (Oct. 2023), [https://www.ajpmonline.org/article/S0749-3797\(23\)00202-7/](https://www.ajpmonline.org/article/S0749-3797(23)00202-7/); Emily Ko & Daniel Saris, *Racial Disparities in Endometrial Cancer Mortality*, PENN LDI (May 23, 2022), <https://ldi.upenn.edu/our-work/research-updates/racial-disparities-in-endometrial-cancer-mortality/>.

people with disabilities and provided the opportunity to highlight additional contexts where people with disabilities are subjected to discriminatory medical treatment.

Between 1907 and 1983, over 60,000 people in the U.S. were sterilized pursuant to eugenics laws, which directed state institutions to sterilize individuals who they deemed “unfit to reproduce.”⁹¹ Some children and adults died from their procedures; others were stripped of autonomy over their reproduction, families, and lives. Disabled women, Latinas, Black women, low-income people, and members of LGBTQI+ communities were disproportionately targeted.⁹² Even after the repeal of eugenics laws, the discriminatory sterilization of people with disabilities and other intersecting identities has continued. As of 2022, thirty-one states and Washington, D.C. allow the forced sterilization of disabled people through guardianship agreements or court orders.⁹³ Additionally, through at least 2013, there is evidence of thousands of people—predominantly Black women with disabilities—being sterilized without consent and sometimes without their knowledge in state prisons.⁹⁴ The Department’s proposed regulatory text would help clarify federal protections against the discriminatory sterilization of individuals with disabilities.⁹⁵ Additionally, as discussed below in our analysis of Proposed Rule § 84.56(c)(2)(ii), we

⁹¹ Nat’l Women’s L. Ctr. & Autistic Women & Nonbinary Network, *Forced Sterilization of Disabled People in the U.S.* 23 (Jan. 2022), <https://nwlc.org/resource/forced-sterilization-of-disabled-people-in-the-united-states/>; Philip R. Reilly, *Eugenics and Involuntary Sterilization: 1907-2015*, 16 ANN. REV. GENOMICS & HUM. GENETICS 351 (2015),

<https://www.annualreviews.org/doi/10.1146/annurev-genom-090314-024930>; Alexandra Minna Stern, *That Time The United States Sterilized 60,000 Of Its Citizens*, HUFFPOST (Jan. 7, 2016), https://www.huffpost.com/entry/sterilization-united-states_n_568f35f2e4b0c8beacf68713.

⁹² Nat’l Women’s L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 91, at 8; Alexandra Stern, *Sterilized in the Name of Public Health: Race, Immigration, and Reproductive Control in Modern California*, 95 AM. J. PUB. HEALTH 1128 (Jul. 2005), <https://pubmed.ncbi.nlm.nih.gov/15983269/>; Nicole Novak et al., *Disproportionate Sterilization of Latinos Under California’s Eugenic Sterilization Program, 1920–1945*, 108 AM. J. PUB. HEALTH 611 (May 2018), <https://pubmed.ncbi.nlm.nih.gov/29565671/>.

⁹³ Nat’l Women’s L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 91, at 15, 34 (explaining that half of these states only permit forced sterilization for individuals already under guardianship, while the other half permit many people to request court orders for sterilization, such as health care providers and entities).

⁹⁴ Shilpa Jindia, *Belly of the Beast: California’s Dark History of Forced Sterilization*, THE GUARDIAN (Jun. 30, 2020), <https://www.theguardian.com/us-news/2020/jun/30/california-prisons-forced-sterilizations-belly-beast>; Cal. State Auditor, *Sterilization of Female Inmates: Some Inmates Were Sterilized Unlawfully, and Safeguards Designed to Limit Occurrences of the Procedure Failed* (Jun. 2013), <https://www.auditor.ca.gov/pdfs/reports/2013-120.pdf>.

⁹⁵ Nat’l Women’s L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 91, at 15.

ask that HHS go further to clarify protections against providers' discriminatory consent-seeking practices.

The Department requested comment on other examples of the discriminatory provision of medical treatment to people with disabilities.⁹⁶ In addition to those discussed above, we highlight that medical treatments provided to disabled individuals based on biases or for the purpose of reducing their perceived burden on caregivers, family, society, or others would fall within the prohibition of Proposed Rule § 84.56(b)(3). As an example, consider the treatment of “Ashley X,” a 6-year-old girl with static encephalopathy. Ashley’s health care providers performed a hysterectomy and breast bud removal, as well as administered high doses of estrogen, to slow her physical growth and her reproductive development.⁹⁷ The reasoning put forth for these treatments was to make it easier for Ashley’s parents to care for her as she aged and to “desexualize” her body in a way that would make her “less vulnerable to sexual assault.”⁹⁸ The procedures were not medically necessary, nor would they have been provided but for Ashley’s disability. This egregious treatment of a child with a disability, in the name of others’ convenience, was discriminatory, and similar growth attenuation therapies would violate Proposed Rule § 84.56(b)(3).

The discriminatory provision of medical treatment can also occur when people with disabilities are forced into psychiatric treatment. Many health care providers hold biased assumptions about people with mental health disabilities and can incorrectly perceive them to be a danger to themselves or others, and this bias is compounded by racial discrimination.⁹⁹ When the provision of involuntary psychiatric treatment is influenced by bias or stereotypes about the person’s disability—as opposed to being based on an

⁹⁶ Proposed Rule, at 63406.

⁹⁷ Julia Epstein & Stephen Rosenbaum, *Revisiting Ashley X: An Essay on Disabled Bodily Integrity, Sexuality, Dignity, and Family Caregiving*, 35 *TOURO L. REV.* 197, 202 (2019), <https://digitalcommons.tourolaw.edu/lawreview/vol35/iss1/9/>; see also David Carlson, Wash. Prot. & Advoc. Sys., *Investigative Report Regarding the “Ashley Treatment”* (May 2007), https://www.disabilityrightswa.org/wp-content/uploads/2017/12/InvestigativeReportRegardingtheAshleyTreatment_May2007.pdf.

⁹⁸ Epstein & Rosenbaum, *supra* note 97, at 202.

⁹⁹ Timothy Shea et al., *Racial and Ethnic Inequities in Inpatient Psychiatric Civil Commitment*, 73 *PSYCH. SERVS.* 1322 (Dec. 2022) (study in large Boston general hospital with a psychiatric unit, showing that Black patients were more likely than white patients to be involuntary admitted); Ambrose H. Wong et al., *Association of Race/Ethnicity and Other Demographic Characteristics with Use of Physical Restraints in the Emergency Department*, 4 *JAMA NETWORK OPEN* (Jan. 2021), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2775602> (finding that during emergency department visits, Black individuals were more likely to be restrained than white individuals).

individualized, clinically-based risk assessment—then such an action would violate Proposed Rule § 84.56(b)(3).

Recipients also violate Proposed Rule § 84.56(b)(3) when they discredit self-reported physical symptoms of a person with a mental health disability and instead only offer mental health services. When providers assume that an individual's mental health condition is the cause of their visit, or that it at least impairs the reliability of their statements, the provider's judgment is not based on a clinical assessment of the physical symptoms but based on biased assumptions about the mental health disability. Individuals who have trauma responses to being in health care settings or those whose physical symptoms are causing increased anxiety or emotional dysregulation are particularly at risk for discriminatory treatment. Bias and stereotypes about their disability can result in the individual being subjected to involuntary psychiatric intervention, including physical and chemical restraint, instead of receiving the medical care they requested. It is our understanding that the involuntary psychiatric treatment of people with disabilities, when influenced by bias or stereotypes, would violate Proposed Rule § 84.56(b)(3).

C. Construction

1. Professional judgment in treatment

We appreciate the Department's inclusion of § 84.56(c)(1), which clarifies the relationship that exists between professional judgment in health care treatment and the proposed nondiscrimination provisions regarding medical treatment. As we noted in § 84.56(b)(1), multiple studies have demonstrated that health care providers disproportionately hold negative attitudes toward and have inaccurate perceptions about people with disabilities.¹⁰⁰ These misperceptions and biases can negatively impact access to and quality of care for people with disabilities.¹⁰¹ Health care providers frequently make treatment decisions based on these erroneous assumptions, including assumptions about quality of life with a disability.¹⁰² Although frequently explicit in nature, discriminatory decision-making in health care can also be grounded in implicit or

¹⁰⁰ See Iezzoni et al., *supra* note 47; Lagu et al., *supra* note 44.

¹⁰¹ See Lisa Iezzoni et al., *Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care?* 41 HEALTH AFFS. 1371, 1373–1374 (2022) (noting that discriminatory attitudes and erroneous assumptions about people with disabilities contribute to health disparities and impact quality of care), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00413>.

¹⁰² Nat'l Council on Disability, Medical Futility Report, *supra* note 52, at 29.

unconscious bias, which is harder to detect. Health care providers often attempt to frame value judgments in treatment decisions as medical decision-making.¹⁰³

We appreciate that the Proposed Rule clearly delineates between professional judgment and prohibited discriminatory treatment. We also agree that nothing in this Proposed Rule requires a health care provider to provide care outside their scope of practice. We remain concerned, however, that given the pervasive bias and misinformation that health care providers hold about people with disabilities, there will be instances where providers will cloak discriminatory decisions as matters of professional judgment or legitimate medical decisions. To mitigate such issues, recipients of federal funds should adopt practices that include requiring disability-competency trainings for health care providers, mandating that health care providers base their treatment decisions on objective criteria including evidence-based treatments and peer-reviewed medical literature, and establishing policies and procedures to ensure that individuals with disabilities are protected from discriminatory decision-making.¹⁰⁴ For example, compliance with § 504 may require recipients such as hospitals or medical facilities to have a structured process for seeking second opinions and an independent review board to mediate decisions to withhold or withdraw life-saving or life-sustaining care and to review other medical treatment denials or limitations, when requested by the impacted individual or their designated medical decision-maker.¹⁰⁵ We note that independent review boards need to have diversity of membership, no conflicts of interest, their own training in disability competency, and a disability rights advocate and patient rights advocate as members.¹⁰⁶ We suggest that HHS amend the text of Proposed Rule § 84.56(c)(1) to make clear that people with disabilities should have a right to challenge professional judgments in medical treatment decision-making.

RECOMMENDATION: Amend § 84.56(c)(1) to add the following:

(iii) Recipients must have a mechanism for allowing individuals with disabilities to appeal medical treatment denials or limitations.

¹⁰³ *Id.* at 32.

¹⁰⁴ *Id.* at 38.

¹⁰⁵ *Id.* at 12. The National Council on Disability suggests specifically that hospitals and medical facilities should establish independent review boards to assist in medical futility decisions for patients deemed incompetent. Further, the report suggests that this board be diverse, independent from the facility or providers, should include disability right advocates, and should strive to protect the due process rights of the person with a disability.

¹⁰⁶ Nat'l Council on Disability, Medical Futility Report, *supra* note 52, at 12.



2. Consent

We appreciate the Department's inclusion of Proposed Rule § 84.56(c)(2) and the clarity it provides around consent in medical decision-making for people with disabilities. We especially appreciate the emphasis the Proposed Rule places on seeking informed consent. As we have noted throughout our comments on Proposed Rule § 84.56, multiple studies have demonstrated that health care providers hold negative biases and assumptions about people with disabilities and often make medical treatment decisions based on ill-informed assumptions.¹⁰⁷ These attitudes worsen health inequities for people with disabilities and create barriers to accessing and receiving quality care.

These discriminatory attitudes and practices were particularly evident during the COVID-19 pandemic, adding to a long and pervasive history of discrimination in medical treatment.¹⁰⁸ Examples of this discrimination include health care providers pressuring people with disabilities or their decision-makers to withhold life-saving or withdraw life-sustaining medical care, to put in place a “Do Not Resuscitate” (DNR) order, or to not pursue aggressive medical treatment.¹⁰⁹ Similarly, providers may pressure individuals with mental health or substance use conditions to accept more restrictive treatment than is necessary, such as in inpatient settings that remove them from their community and support systems, or force them into involuntary hospitalizations based on bias, stereotypes, or discrimination.¹¹⁰ It is critical that health care providers respect and support the autonomy and dignity of individuals with disabilities. Medical facilities and health care providers should not pressure people with disabilities to discontinue care, consent to coercive treatment options, or to accept a guardianship agreement based merely on their faulty perceptions, discriminatory attitudes, or stereotypes about people with disabilities.

As HHS has noted in the preamble to other proposed sections, the discriminatory practice of seeking a court order authorizing the sterilization of a patient on the basis of their disability rather than seeking their informed consent as they would for a non-disabled patient is all too common. HHS should clarify how these practices can violate this section in the preamble to the Final Rule. Moreover, through guardianship and other

¹⁰⁷ See lezzoni et al., *supra* note 47; Lagu et al., *supra* note 44.

¹⁰⁸ See e.g., Proposed Rule, at 63395 (noting that [r]ecent experiences during the COVID-19 public health emergency further illustrate the harms that discrimination can pose).

¹⁰⁹ See *generally*, Nat'l Council on Disability, Medical Futility Report, *supra* note 52.

¹¹⁰ See Shea et al., *supra* note 99; Wong et al., *supra* note 99.

substituted consent arrangements, some disabled people can be forced to continue pregnancies or have abortions against their will.¹¹¹

Another example of discrimination in the context of consent is when a provider requires a disabled person to be subjected to guardianship as a precondition for providing a service, rather than acknowledging and permitting reasonable modifications such as supported decision-making. Similarly, a provider's refusal to treat a disabled person without a guardian may constitute discrimination. To that end, HHS has a critical role to play in connecting the dots between Proposed Rule § 84.68(b)(7), which addresses supported decision-making as a reasonable modification to avoid disability-based discrimination, and § 84.56(c)(2)(i).¹¹² While we appreciate the Department's emphasis on informed consent in § 84.56(c)(2)(i), it should be strengthened by cross-referencing and underscoring health care providers' obligations to provide reasonable modifications in the decision-making process. This may include, for example, modifications to consent processes or hospital visitor policies to allow a designated support person to be present to help facilitate effective communication and/or help a person with a disability decide on the best course of treatment; the use of a supported decision-making arrangement; or the presentation of information about medical treatment decisions in a way that is accessible and readily understandable to the person with a disability.¹¹³

HHS has a critical role to play in elevating the importance of reasonable modifications in the context of consent to empower disabled individuals to decide which medical treatments are right for them. This is especially needed in the context of sterilization and broader sexual and reproductive health care, where there is a long and pervasive history of recipients riding slipshod over individuals' right to consent to or decline treatment.¹¹⁴ People with disabilities can make their own decisions about medical treatments such as sterilization, abortion, pregnancy and related care, and gender affirming care when provided with appropriate, accessible supports tailored to their needs.¹¹⁵ In particular, the preamble should articulate that when a provider or other recipient discriminatorily pursues a court order to authorize sterilization or other coercive reproductive decision or override individual choices about sexual and reproductive health, they may violate § 504.

¹¹¹ *Doe ex rel. Tarlow v. DC*, 489 F.3d 376 (D.C. Cir. 2007) (holding that the District did not violate the constitutional rights of individuals with intellectual disabilities when subjecting them to medical procedures, including abortions, without considering the individuals' wishes).

¹¹² Proposed Rule, at 63474.

¹¹³ *Id.*

¹¹⁴ Emily DiMatteo et al., Ctr. Am. Prog., *Rethinking Guardianship To Protect Disabled People's Reproductive Rights* (Aug. 2022), <https://www.americanprogress.org/article/rethinking-guardianship-to-protect-disabled-peoples-reproductive-rights/>.

¹¹⁵ Nat'l Women's L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 91, at 38.

Moreover, we ask that HHS issue guidance to covered health care providers and entities promoting the use of supported decision-making as a tool to support compliance with this subsection in a sexual and reproductive health care context. Guidance is necessary to ensure that these important applications are not lost in the preamble and reach covered health care practitioners and entities.

3. Providing information

We support the proposed provision that allows providers to inform individuals with disabilities about potential courses of treatment and their implications based on current medical knowledge or the best available objective evidence. The preamble clearly indicates that providers are prohibited from sharing such information in a way that discriminates on the basis of disability or puts undue pressure on the person with a disability (or their authorized representative) to conform to the provider's position.

We suggest clarifying in the Final Rule that any information a provider shares about potential courses of treatment must satisfy all legal standards for accessibility and be presented in a format that is most appropriate to ensure effective communication of that information to the individual with a disability so they can make informed decisions about their care.

§ 84.57 Value Assessment Methods

We support the codification of a prohibition on the use of any measure, assessment, or tool that discounts the value of life on the basis of disability with regards to decisions about eligibility, coverage, and access to services. Tools like the Quality Adjusted Life Years (QALYs) can undervalue the lives of people with disabilities and chronic conditions compared to the lives of people without disabilities.

Since the passage of § 504, Congress has repeatedly recognized the potentially discriminatory impact of such value-assessment tools by limiting or prohibiting the use of QALYs and other similar cost-effectiveness tools in treatment and coverage decisions. In the ACA, Congress prohibited the use of evidence drawn from methodologies that treat “extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill” in determining Medicare coverage, reimbursement, or incentive programs.¹¹⁶ The ACA also prohibited HHS from using dollars per adjusted life years or similar measures that

¹¹⁶ 42 U.S.C. § 1320e-1(c).

discount the value of life because of disability, as thresholds for coverage determinations, reimbursement, or incentive programs in Medicare.¹¹⁷

More recently, Congress limited HHS from using evidence or findings from comparative clinical effectiveness research in a manner that discounts the value of extending a life due to an individual's age, disability, or terminal illness in the process of negotiating prices for certain Medicare drugs.¹¹⁸ These laws reflect an understanding that relying on these tools without accounting for their discriminatory potential can bias coverage and treatment decisions against people with disabilities and chronic conditions.

We have some concerns that the proposed provision hinges on value assessments that discount the value of life extension, while appearing to remain silent on assessments of quality of life improvements that may also systematically disadvantage certain people with disabilities. For example, the Equal Value Life Year Gained (evLYG) assessment does not discount the value of life extension on the basis of disability, and so would appear to be allowed to inform treatment and allocation of resources under this provision. However, the evLYG also factors in a treatment's effect on quality of life using an approach that mimics QALYs.¹¹⁹ That method uses surveys to establish "health utility" weights that are used to quantify improvements in quality of life a treatment may provide. The limited survey tools and utility weights have been rightly critiqued as reductive and potentially discriminatory against people with disabilities.¹²⁰ We urge HHS to consider limiting assessment tools not just based on life extension, but also on methods that might devalue improvements in quality of life on the basis of disability.

We recognize that all the value assessment tools available to researchers and policy-makers have strengths and weaknesses. For example, measures that focus only on life extension, such as cost-per-life-year gained, present only a partial picture of effectiveness because they do not factor in potential improvements in quality of life. Tools that center too much on life extension—even if they treat life extension equally across populations—favor policy decisions that devalue treatments that improve quality

¹¹⁷ 42 U.S.C. § 1320e-1(e).

¹¹⁸ Inflation Reduction Act of 2022, § 11001, 42 U.S.C. § 1320f-3(e)(2)(D).

¹¹⁹ Ken O'Day & Dylan J. Mezzio, *Demystifying ICER's Equal Value of Life Years Gained Metric*, 7 VALUE & OUTCOMES SPOTLIGHT (Jan/Feb. 2021), <https://www.ispor.org/publications/journals/value-outcomes-spotlight/vos-archives/issue/view/overcoming-vaccine-hesitancy-injecting-trust-in-the-community/demystifying-icer-s-equal-value-of-life-years-gained-metric>.

¹²⁰ Nat'l Council on Disability, *Quality-Adjusted Life Years and the Devaluation of Life with Disability* 25–29 (Nov. 6, 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.



of life with little or no effect on life length. Consider a treatment for migraines that greatly improves quality of life, but has no effect on life extension. An assessment tool centered on life extension would show such a treatment to be relatively less cost effective. If such an approach were used for treatment decisions, it could lead to skewed outcomes that systematically discriminate against certain types of disabilities.

We recommend HHS consider altering the wording of this provision to prohibit using assessments that discount quality of life as well as life extension on the basis of disability.

Finally, we support HHS's acknowledgment that this value assessment provision applies to their use in discriminatory conduct, but not to their use in academic research. In the past, when the disability community has spoken out against discriminatory treatment decisions, including value-based assessments, the result has been more robust discourse, not less. The continued elevation of these issues, and resulting engagement with the academic community, will likely stimulate research and innovation in the field. By enumerating the risks attendant with value assessment tools, including prohibited disability discrimination, HHS can similarly prompt more robust and informed research in this area. The National Council on Disability has documented numerous potential alternatives to QALYs that, while having their own limitations, appear less likely to embed social biases against people with disabilities, older adults, and people with chronic conditions in their core methodology.¹²¹ Unfortunately, literature reviews of these alternatives find that they remain largely underdeveloped.¹²² Some health economists and policy-makers continue to argue that the QALY remains "useful" because the research is prevalent and more developed.¹²³ This narrow view perpetuates a cycle that favors further development of QALYs research despite its acknowledged biases and limitations.

By prohibiting the discriminatory use of QALYs for treatment decisions on a broader scale, this Proposed Rule, if finalized with our recommended changes, could accelerate

¹²¹ Nat'l Council on Disability, *Alternatives to QALY-Based Cost-Effectiveness Analysis for Determining the Value of Prescription Drugs and Other Health Interventions* (Nov. 28, 2022), https://ncd.gov/sites/default/files/NCD_Alternatives_to_the_QALY_508.pdf.

¹²² See Josh J. Carlson et al., *Alternative Approaches to Quality-Adjusted Life-Year Estimation Within Standard Cost-Effectiveness Models: Literature Review, Feasibility Assessment, and Impact Evaluation*, 23 *VALUE IN HEALTH* 1523 (2020); Or. Health Evidence Rev. Comm'n, *HERC Use of Quality Adjusted Life Years* (2022), <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Background-HERC%20QALY%20policy.pdf>.

¹²³ Peter J. Neumann & Dan Greenberg, *Is the United States Ready for QALYs?*, 28 *HEALTH AFFS.* 1366 (2009).



the development of more equitable alternatives. These alternatives should include more thoughtful, balanced, multi-method approaches to comparative value assessments that center the perspectives of marginalized groups like people with disabilities, inform transparent resource allocation, and, above all, do not discriminate against people with disabilities or other marginalized groups.

RECOMMENDATION: Amend § 84.57 to prohibit assessments that discount either life extension or quality of life on the basis of disability.

Value Assessment Methods. A recipient shall not, directly or through contractual, licensing, or other arrangements, use any measure, assessment, or tool that discounts the value of life extension **or quality of life** on the basis of disability to deny or afford an unequal opportunity to qualified individuals with disabilities with respect to the eligibility or referral for, or provision or withdrawal of any aid, benefit, or service, including the terms or conditions under which they are made available.

§ 84.60 Children, Parents, Caregivers, Foster Parents, and Prospective Parents in the Child Welfare System

As HHS notes in the preamble, parents with disabilities are more likely to lose custody of their children than their non-disabled counterparts, despite the fact that there is no evidence that they are more likely to be unfit parents or pose a significant risk of child maltreatment.¹²⁴ Removal rates are especially high for parents with a psychiatric disability (as high as 70% to 80%) and intellectual disability (40% to 80%).¹²⁵ Thirteen percent of parents with a physical disability involved in custody cases report discriminatory treatment. Parents who are blind or deaf report high rates of child removal and loss.¹²⁶ Thirty-five states go as far to enumerate disability status as grounds for termination of parental rights.¹²⁷ It is important to address in the preamble how this discrimination intersects with racial discrimination, as Black and American Indian/Alaska Native children are disproportionately represented in the child welfare system.¹²⁸

¹²⁴ Proposed Rule, at 63412; Nat'l P'ship for Women & Fams. & Autistic Self Advoc. Network, *Access, Autonomy, and Dignity: People with Disabilities and the Right to Parent* 11 (Sept. 2021), <https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-parenting.pdf>.

¹²⁵ See Nat'l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 16 (2012), <https://www.ncd.gov/publications/2012/Sep272012/>.

¹²⁶ *Id.*

¹²⁷ Nat'l P'ship for Women & Fams. & Autistic Self Advoc. Network, *supra* note 124, at 11.

¹²⁸ Child Welfare Info. Gateway, Children's Bureau, *Child Welfare Practice to Address*



Proposed Rule § 84.60(b)(3) will promote reproductive justice for people with disabilities by helping to protect them from discriminatory terminations of their parental rights. We greatly appreciate the inclusion of these provisions.

We also appreciate HHS's reiteration in the preamble that medications for opioid use disorder (MOUD) do not constitute the illegal use of drugs, and that "prescribed use of MOUD does not mean that the individual is substituting one addiction for another."¹²⁹ It would be helpful if HHS could clarify that § 84.60 not only prohibits discrimination against individuals who receive MOUD, but that it is discriminatory to require a qualified caregiver, foster parent, companion, or prospective parent who receives MOUD to attend a substance use disorder program that prohibits or restricts the use of MOUD as a condition of maintaining control, custody, or visitation with a child.

Similarly, as the Department notes in its preamble, children with disabilities in the foster care system are all too often placed in congregate care.¹³⁰ We strongly agree with and appreciate HHS's statement that "[c]ongregate care should never be considered the most appropriate long-term placement for children, regardless of their level of disability."¹³¹ The most integrated setting for a child with a disability is their own home.

HHS asks for additional examples of the application of the most integrated setting requirement to child welfare programs and for additional points for consideration regarding integration of children with disabilities in the child welfare system.¹³² HHS also asks whether the list of prohibited activities in the child welfare context is complete.¹³³ The answer to these two questions is intertwined. An additional way in which children with disabilities are discriminated against by child welfare systems and subjected to

Racial Disproportionality and Disparity (April 2021), https://www.childwelfare.gov/pubPDFs/racial_disproportionality.pdf.

¹²⁹ Proposed Rule, at 63414.

¹³⁰ Proposed Rule, at 63415. See also Admin. for Child. & Fams., *A National Look at the Use of Congregate Care in Child Welfare* (May 2015), https://www.acf.hhs.gov/sites/default/files/documents/cb/cbcongregatecare_brief.pdf.

¹³¹ Proposed Rule, at 63415; Sandra Friedman et al., Am. Acad. Pediatrics, *Out-of-Home Placement for Children and Adolescents with Disabilities—Addendum: Care Options for Children and Adolescents with Disabilities and Medical Complexity*. 138 PEDIATRICS (Dec. 2016), <https://publications.aap.org/pediatrics/article/138/6/e20163216/52567/Out-of-Home-Placement-for-Children-and-Adolescents> (noting that "[w]ell established factors that contribute to healthy development that are embedded in most families are missing in even the best congregate care settings").

¹³² Proposed Rule, at 63417.

¹³³ *Id.*



unnecessary removals is when child welfare systems, either explicitly or informally, encourage parents to relinquish custody of their children in order for their children to receive necessary services and support.¹³⁴ Although some states have banned this practice, strong anecdotal evidence suggests that it still takes place.¹³⁵ As recipients of federal funds, child welfare agencies have an independent obligation to provide mental health services and support necessary for children to remain in the most integrated setting. When such agencies encourage parents to relinquish custody in order for their children to access necessary services or based on bias regarding children’s ability to live in the community, they violate § 504. While the specific examples in the “additional provisions” listed in § 84.60(b) are helpful, the provisions fail to capture the discrimination against children with disabilities that takes place when child welfare systems encourage custody relinquishment in order to access supports via the child welfare system, or via any other recipient. We believe an additional explicit prohibition against such actions would be helpful.

RECOMMENDATION: Amend § 84.60(b) to include a new paragraph as follows:

- (5) ***encourage or require a parent of a qualified child with a disability to relinquish custody or control in order for the child to participate in or benefit from child welfare programs and activities.***

§ 84.68 General Prohibitions against Discrimination

We appreciate the Department’s discussion of supported decision-making as a reasonable modification. Supported decision-making, “a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life[,] offers an alternative.”¹³⁶ While there is no one-size-

¹³⁴ Nat’l Disability Rts. Network, *Foster Despair: Improving Access to Education Services for Youth with Intellectual Disabilities in State Custody* (Nov. 2013), https://www.ndrn.org/wp-content/uploads/2019/03/Foster_Despair_Master_FINAL.pdf; Mental Health Am., *Position Statement 47: Custody Relinquishment and Funding for Care and Treatment of Children*, <https://mhanational.org/issues/position-statement-47-custody-relinquishment-and-funding-care-and-treatment-children> (last visited Nov. 8, 2023).

¹³⁵ See, e.g., Christine Herman, Ctr. for Pub. Integrity, *Families Take Drastic Steps to Help Children in Mental Health Crises* (Mar. 16, 2023), <https://publicintegrity.org/health/health-parity/families-help-children-mental-health-crises/>.

¹³⁶ Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported*

fits-all model, supported decision-making arrangements offer an alternative that centers a disabled person in decision-making and empowers self-determination in the identification of their goals, the people they most trust, and who they seek advice from on certain topics.¹³⁷ This self-determination is critical in all areas of a disabled individual's life, including health care. In addition to domestic disability, gender justice, and sexual and reproductive health, rights, and justice organizations, international bodies such as the World Health Organization have uplifted the utility of supported decision-making models in relation to sterilization.¹³⁸

As noted above in our comments on § 84.56(c)(2), discrimination in seeking consent could include a recipient's requirement for an individual with a disability to obtain a guardian or otherwise have some kind of substitute decision-maker in order to obtain treatment. Accepting the use of a supported decision-maker is a reasonable modification. While we strongly support this, we also ask that HHS clarify in the preamble that information should never be shared with a supported decision-maker without consent to avoid situations where recipients reveal information to a support team that the patient does not want. Health care providers should encourage the use of a HIPAA release form so that a patient can consent in writing that their supporter be given access to the patient's private health care information.¹³⁹ Such privacy protections also allow a person to clearly limit what information others have access to and, importantly, retract such consent when there are changes to their support team. Providers need to protect the wishes of the patient as to who knows their confidential health information before releasing it, even to a designated supporter.

§ 84.69 Illegal Use of Drugs

We appreciate the Department's discussion in § 84.69 regarding the difficulty of distinguishing between "current" and "former" use. Additional explanation would be helpful regarding what it means to be "participating in a supervised rehabilitation program" in § 84.69(a)(2)(ii). Substance use disorder, particularly opioid use disorder

Decision-Making, 19 HUM. RTS. BRIEF 8–12 (2012).

<https://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief>.

¹³⁷ Emily DiMatteo et al., *supra* note 114.

¹³⁸ World Health Org., *Eliminating Forced, Coercive, and Otherwise Involuntary Sterilization: An Interagency Statement* 7 (2014),

https://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf.

¹³⁹ Nat'l Disability Rts. Network, *Using Supported Decision Making in Health Care: Frequently Asked Questions* (May 31, 2019), <https://www.ndrn.org/resource/faqs-for-medical-and-other-health-care-providers-supported-decision-making-and-health-care/>.



(OUD), is a chronic condition, and treatment should be ongoing and long-term.¹⁴⁰ Definitions related to current and former use should reflect this.

Treatment with medications buprenorphine and methadone is considered the gold standard of treatment for individuals with OUD. There is overwhelming evidence demonstrating that MOUD are highly effective in reducing overdose deaths, reducing the risk of relapse, reducing engagement in risky activities, and reducing costs associated with health care, criminal justice, and education.¹⁴¹

Initiation of buprenorphine, one of the most effective MOUD, can take place in a physician's office and treatment can continue on an outpatient basis.¹⁴² In fact, when treatment pathways are compared, only treatment with buprenorphine or methadone were associated with reduced risk of overdose, while more "traditional" rehabilitation programs, such as residential services, outpatient counseling, or intensive outpatient or partial hospitalization programs, were not associated with reduced overdose. Thus, the use of the term "supervised rehabilitation program" no longer comports with how many individuals conceptualize and receive their treatment. Instead, we believe it would be more inclusive to state that individuals who are currently under the treatment for a substance use disorder by a medical provider are protected under § 504. We ask that HHS add clarification in the preamble to show that this language is added to modernize the rule and is not intended in any way to restrict the meaning of "supervised rehabilitation program" in 42 C.F.R. § 35.131.

RECOMMENDATION: Amend § 84.69(a)(2)(ii) to state:

- (2) A recipient shall not discriminate on the basis of illegal use of drugs against an individual who is not engaging in current illegal use of drugs and who—
 - (i) Has successfully completed a supervised drug rehabilitation program or has otherwise been rehabilitated successfully;

¹⁴⁰ While we recognize that the statutory carve out for people currently engaged in illegal drug use is just that—a statutory and not a regulatory issue, we would be remiss if we did not note the exclusion has never been based on principled reasoning, and certainly no longer comports with our current understanding of substance use disorder as a chronic condition.

¹⁴¹ Corey Davis et al., Nat'l Health L. Prog., *Medication Assisted Treatment for Opioid Use Disorder: The Gold Standard* (May 16, 2018), <https://healthlaw.org/resource/medication-assisted-treatment-for-opioid-use-disorder-the-gold-standard/>.

¹⁴² Sarah Wakeman et al., *Comparative Effectiveness of Different Treatment Pathways for Opioid Use Disorder*, 3 JAMA NETWORK OPEN (Feb. 2020), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2760032>.



- (ii) Is participating in a supervised rehabilitation program. ***A supervised rehabilitation program includes treatment for a substance use disorder received under the supervision of a medical professional or other licensed practitioner.***
- (iii) Is erroneously regarded as engaging in such use.

Last, we request that HHS delete § 84.69(b)(2), which permits a drug rehabilitation or treatment program to deny participation to individuals who engage in illegal use of drugs while they are in the program. This provision is not required by statute, is based on an outdated understanding of how drug treatment works, and can serve to deny individuals access to treatment of a disorder just for exhibiting symptoms of that disorder.

§ 84.70 Maintenance of Accessible Features

We appreciate the clarification that temporary or isolated obstructions or mechanical failures would not be considered violations of § 504. However, we are concerned that the way this section is worded could potentially create confusion as to a recipient's responsibility to continue to provide access to services while obstructions or mechanical failures persist. Even a temporary obstruction like maintenance being done to a facility entry way or mechanical failure of a building's elevator can deny equal opportunities and thus discriminate against individuals with disabilities until the maintenance is completed. We suggest that HHS amend the language in this paragraph to clarify a recipient's responsibility to provide notification of obstructions and maintenance and reasonable modification for services in the event that temporary obstructions or maintenance of accessible features happen or are expected to occur.

RECOMMENDATION: Amend the end of § 84.70 as follows:

In the event that temporary obstructions or maintenance to accessible features could deny an individual with disabilities' access to accessible features, services, or programs, the recipient is responsible for providing advanced notice of temporary obstructions or maintenance of accessible features and should provide reasonable modifications for those services which are experiencing a disruption until the maintenance or repairs are resolved.

§ 84.73 Service Animals

We support HHS's proposal to revise the definition of service animals in § 84.73 to correspond to the ADA Title II regulations. We support HHS clarifying what distinguishes a service animal from an emotional support animal and appreciate that recipients are given clear guidance on what questions they may ask of the animal's handler in order to distinguish a service animal from a support animal or pet. In relation to that point, we also appreciate that people with disabilities cannot be compelled to present onerous documentation certifying their need for a service animal. Similarly, the inclusion of § 84.73(b) clarifying specific instances in which a recipient may deny the use of a service animal, and limiting those instances to (1) the handler cannot control the service animal and (2) the animal is not housebroken, will serve to set clear boundaries and expectations about the legality of the service animal's presence for the recipient and the animal handler's responsibilities alike. Likewise, in § 84.73(f), we support that recipients are given clear limits as to what questions they may ask to determine the necessity of a service animal and that the animal's handler does not need to produce documentation, such as proof that the animal has been certified, trained, or licensed as a service animal.

§ 84.74 Mobility Devices

We support and agree with HHS expanding the definition of mobility devices, modeling it on ADA regulation, 28 CFR § 35.137. We appreciate that HHS makes the recipients responsible for proving a particular type of device cannot be accommodated because of legitimate safety requirements, which must be based on actual risks. Consistent with the similar limitations proposed in § 84.73, we appreciate that recipients are given clear guidance on what questions they may ask to determine the necessity of a person's use of a mobility device. We support the option given to the user of the mobility device that they may choose to present a disability placard or license as credible assurance of their need for that device, but a recipient cannot demand that a user have a placard or license to use a mobility device. We also appreciate that HHS acknowledges that some people who use mobility devices have the ability to walk and stand and there are others that may have hidden disabilities, which does not negate the fact they have a need for the mobility device. Last, we appreciate that the definition in Proposed Rule § 84.10 is clear that all wheelchairs, whether manual or power driven, are excluded from "other powered mobility devices."

§ 84.76 Integration

We strongly support HHS's inclusion of this section and attention to the importance of integration, and appreciate the Department's attention to this critical issue.

For the reasons discussed above in § 84.10 regarding the definition of "most integrated setting," below we offer suggestions to better ensure that disabled individuals are not isolated in a setting that exists in a community but are actually integrated with their communities to the greatest extent possible, as is their right under § 504.

There has been a rise in settings, both residential and otherwise, that purport to create communities within the settings themselves or claim they are community-based because they exist within a neighborhood or city. But the experience of individuals within those settings is very isolated or involves interactions primarily with disabled peers and employees of the setting. Some of the settings that currently use or seek to use federal funds targeted for community-based services are new versions of institutional settings. They may be on farms, campuses, storefronts, business parks, etc., but the experience of an individual is very similar to that of someone in state-run institutions. The same activities that were offered in the older state-run institutions are now offered in a slightly different, but equally segregated setting. These settings claim to be integrated because they have outside volunteers come visit. A tour of a state-run institution for people with intellectual and developmental disabilities and one of a farmstead for people with intellectual and developmental disabilities often reveals a very similar experience for the residents in terms of community integration. It is important that both such settings are considered segregated for purposes of federal funding, and that the definitions do not become blurred.

The central question of whether a person is segregated from their community is the extent to which they are supported in interacting with non-disabled peers and activities in the broader community (not within the setting or a setting's large campus). Choice and autonomy in daily activities are also critical. However, choice of a segregated setting does not make that setting somehow more integrated. Importantly, co-opting terms such as "community", "integration", and "choice" cannot be what determines the nature of setting. It must be based on the actual experience of an individual in that setting. For example, even if segregated settings create something they call a "community" within their setting, this is not the same "community" that is the subject of the legislative history of § 504, and the ADA, or the related body of case law regarding ending the segregation

of people with disabilities.¹⁴³ Importantly, defining integration in § 504 does not prohibit segregated settings from existing, but does limit the use of federal funds in such settings as is appropriate given the language and protections of § 504. The Proposed Rule plays an important role in defining integration to help prevent people with disabilities becoming segregated once again in institutional settings.

Below, we share feedback on the specific language of § 84.76. But as a preliminary matter, we are concerned that HHS’s statement in the preamble for § 84.76 related to the scope of the § 504 NRPM may be misleading and unnecessarily confusing. Here, HHS states:

While the Department is also proposing an integration mandate provision under Section 1557, that provision relates to benefit design in health insurance coverage or other health-related coverage. The proposed integration provision in this rule does not relate to benefit design or other health insurance coverage issues. The obligations in this proposed provision include many that are also articulated in Section 1557, but also extend to a broader range of programs and activities by recipients of Federal financial assistance.¹⁴⁴

While we appreciate HHS’s intent to differentiate the discussion of § 504 and § 1557, including an explanation that § 504 applies to a broader swath of programs and activities than § 1557, HHS’s statement could be misconstrued to mean that § 504 does not prohibit discriminatory benefit design in health insurance. It does.

As § 504 exists today, it encompasses and protects against discriminatory benefit design in health insurance. By prohibiting recipients from “utiliz[ing] criteria or methods of administration... that have the purpose of or effect of defeating or substantially impairing accomplishment of the objectives of the recipient’s program or activity” or otherwise discriminates against people with disabilities, § 504 reaches discriminatory benefit design in health insurance.¹⁴⁵ Additionally, the ACA explicitly prohibited discriminatory health insurance practices that had previously long been allowed and unsuccessfully challenged in court as disability discrimination under § 504, including discriminatory benefit design, forever changing what would and would not be allowed in health

¹⁴³ As discussed in the preamble to the Proposed Rule, there is a long history of cases and guidance addressing the right of disabled people to be integrated in their communities and not segregated. Proposed Rule, at 63482–63847.

¹⁴⁴ Proposed Rule, at 63483.

¹⁴⁵ 45 C.F.R. § 84.4(b)(4).

insurance.¹⁴⁶ Because § 1557 of the ACA explicitly references § 504 in its creation of a health care-specific civil right that protects against discrimination in both access to and content of health care coverage, § 504, as incorporated by § 1557, reaches discriminatory benefit design.¹⁴⁷ *Alexander v. Choate* does not prohibit this interpretation of § 504, although some courts have misinterpreted *Choate* to reason that § 504 does not reach the “content” of a health insurance policy, but rather only the ability to “access” coverage.¹⁴⁸ HHS should acknowledge the role of § 504 in the analysis of and protection against discriminatory benefit design. Therefore, we recommend HHS delete this misleading language in the preamble for § 84.76 and clarify that § 504 prohibits discriminatory benefit design in the § 504 Final Rule.¹⁴⁹

A. Application

We are not clear on the function of § 84.76(a) regarding applicability as opposed to the other regulatory requirements for applicability stated in Proposed Rule § 84.2. The community integration section should already apply to “programs or activities that receive Federal financial assistance from the Department and to recipients that operate such programs or activities.” We understand and appreciate the Department’s explanation that this is included to ensure that readers understand that *Olmstead* obligations apply outside of the residential context, but the proposed language does little to actually clarify this. To restate the section here may serve to unintentionally limit this section or the applicability of other sections. We question the necessity of restating it and whether it may have unintended consequences.

¹⁴⁶ Brief for Nat’l Health L. Prog. & Disability Rts. Cal. as Amici Curiae Supporting Respondents at 6–9, *CVS Pharmacy, Inc. v. Doe*, 141 S.Ct. 2882 (2021) (No. 20-1374), <https://healthlaw.org/resource/amicus-brief-from-national-health-law-program-in-cvs-v-doe/>.

¹⁴⁷ *Id.* at 16–22; Brief for Nat’l Health L. Prog. & Northwest Health L. Advocates as Amici Curiae Supporting Plaintiffs-Appellants at 14, *Schmitt v. Kaiser Found. Health Plans Wash.*, 965 F.3d 945 (9th Cir. 2020) (No. 18-35846), <https://healthlaw.org/resource/schmitt-v-kaiser-found-health-plan-washington-amicus-brief/>.

¹⁴⁸ See Brief for Disability Rts. Educ. & Def. Fund et al., as Amici Curiae Supporting Neither Party at 8–12, *Doe v. CVS Pharmacy, Inc.*, 982 F.3d 1204 (9th Cir. 2020) (No. 19-15074), <https://dredf.org/wp-content/uploads/2019/07/DREDF-Doe-v-CVS-Amicus-7-1-2019-Accessible.pdf>; Brief for Disability Rts. Educ. & Def. Fund et al., as Amici Curiae Supporting Plaintiffs-Appellants at 9–13, *E.S. v. Regence Blueshield*, 812 F.App’x. 539 (9th Cir. 2020) (No. 18-35892), <https://dredf.org/wp-content/uploads/2019/02/DREDF-et-al-Amicus-Brief-E-S-v-Regence-1-30-2019.pdf>.

¹⁴⁹ For more detailed discussion on features of discriminatory benefit design and why § 504 reaches discriminatory benefit design, see Nat’l Health L. Prog., *supra* note 27, at 106–126, 136–142.



B. Discriminatory Action Prohibited

We are concerned that there appears to be a disconnect between the definition of “most integrated setting” in § 84.10, which highlights the need for settings to be administered in the most integrated setting to “the fullest extent possible,” and the proposed language in § 84.76(b), which focuses on “unnecessary segregation.” Referring to “unnecessary segregation” assumes segregation may be necessary and imposes a qualification that is not in statute nor is it in most current guidance. While the *Olmstead* decision discussed unnecessary institutionalization, and part of the *Olmstead* test is whether a community placement is appropriate, the central thrust of the decision is about the right to live in and be engaged in the community. We are concerned that the use of “unnecessary segregation” may be used to justify the segregated placement of individuals that could be served in the community with appropriate supports. The determination of whether something is discriminatory should focus on whether the program or activity is the most integrated setting appropriate. The use of the qualifier “unnecessary” allows for opponents of integration to raise concerns that counterbalance the right to integration, and creates a dichotomy that overemphasizes the question of whether an individual is institutionalized or not. Instead, there is a range of integration outside of an institution, and a person has the right to be integrated with their communities to the extent possible. For these reasons, we would suggest removing the phrase “unnecessary segregation,” and instead framing discrimination as a determination of whether a program or activity is administered in the most integrated setting.

RECOMMENDATION: Amend § 84.76(b) as follows:

- (b) *Discriminatory action prohibited.* A recipient shall administer a program or activity in the most integrated setting appropriate to the needs of a qualified person with a disability. Administering a program or activity in a manner that **does not provide individuals the most integrated setting** ~~results in unnecessary segregation of persons with disabilities~~ constitutes discrimination under this section.

C. Segregated Settings

In § 84.76(c), we again suggest removing the word “unnecessary,” and instead focusing on the characteristics that limit integration. We also suggest that the characteristics of a segregated setting are included as a non-exhaustive list, and that an example be added to clarify that segregation takes place in residential settings and in daytime activities. Last, we suggest deleting the word “policies” to demonstrate that both policies and



practices that result in segregation are prohibited. For example, a setting could have a policy permitting visitors, but in practice restrict them. As noted above in comments regarding the definition of “most integrated setting,” a setting that technically allows a person to leave to engage in community activities, but where an individual does not have access to transportation or needed support staff to actually do so, is not actually integrated. A setting that technically permits choice of activities, but where the choice is exceedingly limited due to what a setting is willing to offer, is likewise a characteristic of a segregated setting. The affirmative obligation of a recipient is not just to have policies that permit integration, but to take proactive steps to avoid discrimination and support integration.

RECOMMENDATION: Amend § 84.76(c) as follows:

- (c) *Segregated setting.* A segregated setting is one in which people with disabilities are unnecessarily separated from people without disabilities. Segregated settings **include: settings that** are populated exclusively or primarily with individuals with disabilities **or that provide for daytime activities primarily with other individuals with disabilities**, and may be characterized by regimentation in daily activities; lack of privacy or autonomy; and policies limiting visitors or limiting individuals' ability to engage freely in community activities and to manage their own activities of daily living.

D. Specific Prohibitions

We appreciate the recognition in the preamble that an individual does not have to be institutionalized to be discriminated against based on disability, and that discrimination also occurs when people experience service cuts, service denials, inadequate discharge planning, or other actions that put people at risk of institutionalization.¹⁵⁰ We fully support reflecting the right to community integration currently reflected in case law and federal guidance, and we agree with the statement that individuals do not have to wait to be harmed to assert a claim.¹⁵¹

However, we believe § 84.76(d)(4) would be strengthened if it was made clearer that the language regarding not waiting until harm occurs is more clearly not limited to institutionalization or serious risk of institutionalization. As discussed above, the right to not be segregated from the community is not merely implicated when an individual is in

¹⁵⁰ Proposed Rule, at 63484–86.

¹⁵¹ *Id.* at 63485.



an institution versus in the community, but it also arises when a person is not integrated with their community to the extent possible or appropriate to their needs. Several cases have recognized the right to not be segregated from the community.¹⁵² We are concerned that leaving the statement regarding not needing to wait until harm occurs in the paragraph regarding risk of institutionalization may be unintentionally limiting. Thus, we suggest moving the language regarding not needing to wait until harm has occurred from paragraph (d)(4) to subsection (d).

Furthermore, we recommend moving language in (d)(4) that addresses planning, service design, funding, and service implementation practices to (d)(1), so likewise this prohibition is not limited to institutionalization or serious risk of institutionalization, but rather applies to any type of segregation.

RECOMMENDATION: Amend § 84.76(d) as follows:

- (d) *Specific prohibitions.* The general prohibition in paragraph (b) of this section includes but is not limited to the following specific prohibitions, to the extent that such action results in unnecessary segregation, or serious risk of such segregation, of persons with disabilities. ***Individuals with disabilities need not wait until the harm of institutionalization or segregation occurs to assert their right to avoid unnecessary segregation.***
- (1) Establishing or applying policies or practices that limit or condition individuals with disabilities' access to the most integrated setting appropriate to their needs; ***Policies and practices include planning, service system design, funding, or service implementation practices that result in segregation.***
 - (2) Providing greater benefits or benefits under more favorable terms in segregated settings than in integrated settings;
 - (3) Establishing or applying more restrictive rules and requirements for individuals with disabilities in integrated settings than for individuals with disabilities in segregated settings; or
 - (4) Failure to provide community-based services that results in institutionalization or serious risk of institutionalization. ~~This category includes, but is not limited to planning, service system design, funding, or service implementation practices that result in institutionalization or serious risk of institutionalization. Individuals with disabilities need not wait until the harm of institutionalization or~~

¹⁵² *Supra* note 36.

~~segregation occurs to assert their right to avoid unnecessary segregation.~~

E. Civil Rights Obligations as Distinct from Medicaid Law and Regulations

We support HHS's explanation in the preamble that civil rights obligations are distinct and separate from Medicaid law and regulations. We also appreciate HHS's acknowledgement that providing services beyond what a State currently provides under its Medicaid program may not be fundamental alteration. Determination of compliance with § 504 is separate from a determination of compliance with the Medicaid statute and its rules. As the Department notes in the preamble, CMS approval of State Transition Plans under the HCBS Settings Rule does not constitute a determination of compliance with the ADA and § 504.

F. Incorporation of Guidance

After the Supreme Court announced the *Olmstead* decision, HHS (at the time through HCFA) issued a series of four Dear State Medicaid Director Olmstead Update Letters providing critical guidance to states on the proper implementation of the *Olmstead* decision.¹⁵³ Currently pending before the Supreme Court are two cases, *Loper Bright Enterprises v. Raimondo* (No. 22-451) and *Relentless v. Dept. of Commerce* (No. 22-1219), that could drastically reduce the instances where courts defer to agency guidance documents such as these or eliminate such deference altogether. We suggest that it will be critical for HHS to review each of the Olmstead Update Letters and explicitly incorporate their required activities into these regulations.

¹⁵³ Health Care Fin. Agency, *Dear State Medicaid Director* (Jan. 4, 2000) (Olmstead Update No. 1), <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/downloads/SMD011400C.pdf>; Health Care Fin. Agency, *Dear State Medicaid Director* (Jul. 25, 2000) (Olmstead Update No. 2), <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/downloads/smd011400a.pdf>; Health Care Fin. Agency, *Dear State Medicaid Director* (Jul. 25, 2000) (Olmstead Update No. 3), <https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd072500b.pdf>; Health Care Fin. Agency, *Dear State Medicaid Director* (Jan. 10, 2001) (Olmstead Update No. 4), <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/downloads/smd011001a.pdf>.



§ 84.83 Accessibility of Kiosks

We support HHS's inclusion of Proposed Rule § 84.83, which would provide general nondiscrimination requirements for programs or activities provided through or with the use of kiosks. We are grateful that HHS acknowledged such explicit protections are timely and necessary when considering the increasingly common use of kiosks in health care settings. Kiosk usage, including basic computer or tablet setups, are also becoming more common in local social services offices as one of the main mechanisms to apply for, renew, and otherwise access information about a person's public benefits, and thus are a major avenue for people to receive and maintain necessary benefits. Moreover, these nondiscrimination requirements should encompass kiosk accessibility, both in terms of the actual information exchange that occurs within the kiosk system and where kiosks are physically located in recipient settings. For example, kiosks should be both physically accessible to wheelchair users and include the necessary auxiliary aids for people with visual, hearing, and other impairments.

HHS also requested comment on whether a definition of "kiosks" is necessary, and if so, solicited comment on the proposed definition in § 84.10.¹⁵⁴ We support HHS's proposed definition of "kiosks," particularly its inclusion of basic computer or tablet setups, and we urge HHS to maintain this expansive definition in the Final Rule.

§§ 84.90–84.94 Accessible Medical Diagnostic Equipment

We strongly support the Department's proposed incorporation of the U.S. Access Board's 2017 Standards for Accessible Medical Diagnostic Equipment ("MDE Standards"), 36 C.F.R. Part 1195, into §§ 84.90–84.94. The MDE Standards, which implement § 510 of the Rehabilitation Act, set forth minimal technical criteria for the accessibility of MDE for people with disabilities where health programs or activities are conducted.¹⁵⁵ Incorporating these standards into § 504 is a necessary step towards improving access to diagnostic health care services for individuals with disabilities.

As HHS has identified, people with disabilities continue to fare worse on a broad range of health indicators than nondisabled individuals. For example, adults with disabilities are 58% more likely to experience obesity, three times more likely to be diagnosed with diabetes, and nearly four times more likely to have early-onset cardiovascular

¹⁵⁴ Proposed Rule, at 63424.

¹⁵⁵ 29 U.S.C. § 794f; 36 C.F.R. Part 1195.



disease.¹⁵⁶ They are also more likely to have high blood pressure and experience symptoms of psychological distress.¹⁵⁷

These disparities in health outcomes are closely linked to a lack of timely access to quality primary and specialty health care services. Both children and adults with disabilities are more than twice as likely as their nondisabled counterparts to report unmet health care needs.¹⁵⁸ Further, adults with disabilities are significantly less likely to receive preventative and diagnostic health services, including primary care appointments, cervical cancer screenings, and mammograms.¹⁵⁹

Disparities in access to care can be traced, in part, back to a widespread lack of accessible MDE in provider facilities. Examination tables, weight scales, and imaging equipment are critical to health maintenance and diagnosis, yet they are often not accessible for people with mobility disabilities.¹⁶⁰ For example, a recent study of nearly 4,000 primary care offices in California found that only 19% of facilities had accessible examination tables and only 11% of facilities had accessible scales.¹⁶¹ Even when provider facilities have accessible MDE, staff are often not properly trained in how to use the equipment, leading to underutilization.¹⁶²

¹⁵⁶ Yee et al., *supra* note 51, at 32; see also, e.g., Valerie L. Forman-Hoffman et al., *Disability Status, Mortality, and Leading Causes of Death in the United States Community Population*, 53 MED. CARE 346 (Apr. 2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5302214/>; Elham Mahmoudi & Michelle Meade, *Disparities in Access to Health Care Among Adults with Physical Disabilities: Analysis of a Representative National Sample for a Ten-Year Period*, 8 DISABILITY HEALTH J. 182 (Apr. 2015), <https://pubmed.ncbi.nlm.nih.gov/25263459/>.

¹⁵⁷ Lisa Iezzoni et al., *Trends in U.S. Adult Chronic Disability Rates Over Time*, 7 DISABILITY HEALTH J. 402 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4167341/>.

¹⁵⁸ Yee et al., *supra* note 51, at 31.

¹⁵⁹ See e.g., H. Stephen Kaye, *Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act*, 109 AM. J. PUB. HEALTH 1015 (Jul. 2019), <https://pubmed.ncbi.nlm.nih.gov/31095413/>; Michael Stillman et al., *Healthcare Utilization and Associated Barriers Experienced by Wheelchair Users: A Pilot Study*, 10 DISABILITY & HEALTH J. 502 (Oct. 2017), <https://pubmed.ncbi.nlm.nih.gov/28245968/>; Brian Armour et al., *supra* note 84, at 406–14.

¹⁶⁰ Nat'l Council on Disability, *Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* 16 (May 20, 2021), <https://ncd.gov/publications/2021/enforceable-accessible-medical-equipment-standards> [hereinafter MDE Report].

¹⁶¹ Nancy Mudrick et al., *Presence of Accessible Equipment and Interior Elements in Primary Care Offices*, 3 HEALTH EQUITY 275, 275–79 (Jun. 2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6585465/>.

¹⁶² Nat'l Council on Disability, MDE Report, *supra* note 160, at 16.

The lack of access to accessible MDE compromises the quality of care that people with disabilities receive, and it can lead to missed or delayed diagnoses of potentially life-threatening conditions.¹⁶³ Further, the lack of accessible MDE in provider facilities has been shown to negatively impact the mental health of people with disabilities and cause many individuals to forgo needed preventative care.¹⁶⁴

We commend HHS for proposing to require covered entities to comply with the MDE Standards and believe that, upon full adoption, it will make a significant impact on the long-term health outcomes of people with disabilities. With that in mind, we offer a few suggestions to further strengthen the Department’s detailed requirements:

A. Timeline for Accessible Weight Scales

While we recognize and appreciate that HHS needs to allow covered entities sufficient time to purchase, lease, or otherwise acquire accessible MDE, we believe that the proposal of allowing entities two years to comply with the requirement for accessible weight scales (Proposed Rule § 84.92(c)) is excessively lenient. The ACA mandated the development of the accessible MDE standards in 2010; the U.S. Access Board released proposed standards in 2012; and the standards were finalized in 2017. Recipients have been on notice that accessible MDE will be required for over thirteen years and they have had access to what those specific standards will be for six years. Additionally, accessible weight scales are readily available on the market today. Allowing recipients another two years to obtain accessible weight scales is unreasonable and will only further delay disabled individuals’ rights to basic diagnostic health care services. Instead, we recommend HHS shorten the requirement in Proposed Rule § 84.92(c), as it relates to weight scales, to one year. For accessible tables, we agree that a two-year timeframe is appropriate, because market supply may not be as ample as that of accessible weight scales.

¹⁶³ Nat’l Council on Disability, MDE Report, *supra* note 160, at 16–20.

¹⁶⁴ See, e.g., Amanda Reichard et al., *Prevalence and Reasons for Delaying and Foregoing Necessary Care by the Presence and Type of Disability Among Working-Age Adults*, 10 DISABILITY & HEALTH J. 39, 39–47 (2017), <https://pubmed.ncbi.nlm.nih.gov/27771217/>; Carrie Basas, *Advocacy Fatigue: Self-Care, Protest, and Educational Equity*, 32 WINDSOR Y.B. ACCESS TO JUST. 37 (2015), <https://wyaj.uwindsor.ca/index.php/wyaj/article/view/4681>.



B. Timeline Requirements for Other MDE

Notably absent from the Department's proposal is a timeline for compliance for the MDE Standards that apply to equipment other than examination tables and weight scales, such as radiological equipment, mammography equipment, dental and optical exam equipment, and other equipment used for diagnostic purposes by health care providers. The scoping requirements in Proposed Rule § 84.92(b) outline the extent to which different types of facilities that use MDE must have accessible equipment units. However, unlike subsection (c), there is no timeline provided for full compliance with these requirements. In the absence of an explicit timeline, it appears that facilities only need to comply with these requirements on a rolling basis, as new equipment is purchased, leased, or otherwise acquired, pursuant to the new equipment requirements outlined in Proposed Rule § 84.92(a). While we strongly agree with the inclusion of § 84.92(a), which applies to all MDE, we also think that—like with examination tables and weight scales—there needs to be an outer limit for full compliance with the MDE Standards. We recommend HHS require recipients to comply with the scoping requirements of Proposed Rule § 84.92(b) within two years after the effective date of the Final Rule.

C. Alternative Accessible Locations

In § 84.93(b), the Department proposes to allow covered entities to comply with the accessible MDE requirements through other methods, including through “reassignment of services to alternate accessible locations” and “delivery of services at alternate accessible sites.” We are concerned that this provision will allow recipients to evade the accessible MDE requirements. While we appreciate that the Department recognized in the preamble that “such an arrangement would not provide an equal opportunity . . . if it was, for example, significantly less convenient for the patient, or if the visit to a different location resulted in higher costs for the patient,” we think it is important to codify this point in the text of the Proposed Rule.¹⁶⁵ Without it, we are concerned that people with disabilities will continue to have to travel farther, wait longer, or otherwise face unequal treatment when trying to access diagnostic health care services.

RECOMMENDATION: Amend § 84.93(b) as follows:

Methods. A recipient may comply with the requirements of this section through such means as reassignment of services to alternate accessible locations, home visits, delivery of services at alternate accessible sites, purchase, lease, or other

¹⁶⁵ Proposed Rule, at 63455.

acquisition of accessible MDE, or any other methods that result in making its programs or activities readily accessible to and usable by individuals with disabilities, ***as long as such an arrangement provides an equal opportunity for the patient. An arrangement does not provide an equal opportunity if, for example, it is significantly less convenient for the patient or if it results in higher costs for the patient.***

While this Proposed Rule is a significant step towards advancing health equity for people with disabilities, we also encourage the Department to consider expanding the scope of its equipment standards and requirements in future rulemaking. The 2017 MDE Standards primarily focus on ensuring access for people with disabilities that impact their mobility, strength, and physical functioning. We also encourage HHS to consider adopting standards pertaining to uses of MDE by people with sensory disabilities, intellectual or developmental disabilities, and other disabilities. For example, the current standards outline very specific requirements related to the size; height adjustment; head, back, and leg supports; and transfer to MDE such as an examination table. However, the standards lack similarly detailed requirements that focus on, for example, ensuring communication access and meeting an individual's sensory sensitivity needs while they are interacting with diagnostic equipment.¹⁶⁶

Additionally, we urge the Department to consider expanding the scope of the standards to encompass equipment not only used in medical diagnostics, but also equipment and devices used in medical treatment. This may include, for example, cancer treatment and dialysis chairs, surgical tables and chairs, and rehabilitative or habilitative tables and chairs. It should also include at-home medical diagnostic and treatment equipment, such as CPAP and BIPAP machines, glucose monitors, blood pressure monitors, and other digital equipment. For example, many people with disabilities use infusion pumps, which allow them to self-administer nutrients and/or medications in the comfort, convenience, and privacy of their own home. Infusion pump users also sometimes have disabilities that impact their vision or motor control. In order to ensure equal access to this device, it should have universally designed controls and switches; high contrast colors and/or raised letters on the controls; large font displays and/or auditory feedback options; and

¹⁶⁶ There is one MDE Standard, M305.1, that addresses communication access during a diagnostic procedure. However, it comprises of one sentence and it fails to take into account the nuances of different communication and sensory disabilities and different circumstances under which a patient may need to interact with or operate the equipment or communicate with a health care professional who is facilitating the diagnostic procedure. See U.S. Access Board, *Medical Diagnostic Equipment Accessibility Standards, Chapter 3: Technical Requirements*, <https://www.access-board.gov/mde/chapter-m3/> (last visited Oct. 20, 2023).

the capacity to set auditory, visual, and tactile alerts.¹⁶⁷ Infusion pumps are just one example of a type of equipment that the standards can and should be expanded to, in order to fully effectuate the equal access rights of people with disabilities.

Need for Data Collection for Civil Rights Enforcement

The strong civil rights protections that HHS seeks to codify in this Proposed Rule require meaningful monitoring and enforcement. As HHS has acknowledged in its 2022 Equity Action Plan, it needs demographic information on individuals served through its programs and activities to measure the effectiveness of civil rights protections, facilitate accessibility, and address identified shortcomings.¹⁶⁸ Improving data collection in health care for people with disabilities is also a core recommendation in the National Council on Disability's 2022 Framework to End Disparities of People with Disabilities.¹⁶⁹

Despite the repeated acknowledgment of the need for disability demographic data, and HHS's recent progress in improving demographic data collection for other populations, disability data is rarely collected by programs, providers, and health plans.¹⁷⁰ HHS has not set expectations for recipients to collect information on people with disabilities as a demographic population, although HHS has long established standards for doing so.¹⁷¹

¹⁶⁷ Disability Rts Educ. & Def. Fund, *Medical Equipment*, <https://dredf.org/public-policy/dredfs-model-comments-on-the-doj-anprm/medical-equipment/> (last visited Oct. 20, 2023).

¹⁶⁸ HHS has incorporated demographic data collection into its 2022 Equity Action Plan, U.S. Dep't Health & Hum. Servs., *Equity Action Plan* (Apr. 2022), <https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf>, and demographic data collection has long been a stated priority for its subagencies; see, e.g., Ctrs. for Medicare & Medicaid Servs., *The CMS Equity Plan for Improving Quality in Medicare* (Sept. 2015), https://www.cms.gov/about-cms/agency-information/omh/omh_dwnld-cms_equityplanformedicare_090615.pdf; Ctrs. for Medicare & Medicaid Servs., *CMS Framework for Health Equity 2022-2032* (Apr. 2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>; Ctrs. for Medicare & Medicaid Servs., *CMS Strategic Plan, Pillar: Health Equity* (Aug. 2022), https://www.cms.gov/sites/default/files/2022-04/Health%20Equity%20Pillar%20Fact%20Sheet_1.pdf.

¹⁶⁹ Nat'l Council on Disability, *Framework to End Disparities of People with Disabilities* (Feb. 2022), <https://ncd.gov/sites/default/files/NCD-Framework-to-End-Health-Disparities-of-People-with-Disabilities.pdf>.

¹⁷⁰ See Silvia Yee & Mary Lou Breslin, Disability Rts. Educ. & Def. Fund & Nat'l Health L. Prog., *This Data, Not That Data: Big Data, Privacy, and the Impact on People with Disabilities*, 2–3 (Mar. 2023), https://healthlaw.org/wp-content/uploads/2023/03/This-Data-Not-That-Data_Disability-Rights-Education-and-Defense-Fund_FINAL.pdf.

¹⁷¹ U.S. Dep't Health & Hum. Servs., Off. Assistant Sec'y Evaluation & Planning, *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary*



Disability advocates have asked for HHS to go further in implementing data collection on disability and functional status as part of program and plan administration, as well as in the electronic health record, but progress has been minimal.¹⁷² Rather, our understanding of disability is mainly derived from limited data sets in surveys and research.¹⁷³

The current method of identifying and studying the experiences of people with disabilities through survey administration is inadequate to address accessibility needs and to ensure the civil rights protections enumerated by this Proposed Rule. Many of the surveys currently used to understand the experiences of people with disabilities in federal programs do not collect sufficient data to disaggregate by more granular demographic categories, such as people with intellectual or developmental disabilities, or illuminate intersectional experiences, such as Latino/a/e/x people with disabilities.¹⁷⁴ Information captured through surveys also cannot be used to determine accessibility needs for individuals in the same way that program administration data can. Because surveys generate anonymized data, they cannot be connected to a particular individual's needs. On the contrary, disability demographic data collected through program administration has the potential to facilitate programs, plans, and providers meeting the civil rights requirements of § 504 and this Proposed Rule. For example, collecting functional limitation information will help providers to identify patients' need for accommodations during clinical visits and hospitalizations, increasing the likelihood that accommodations needed for equally effective health care will be provided in a timely and consistent way.¹⁷⁵ Collecting language data of individuals (and their parents and guardians for

Language, and Disability Status (2011), <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>.

¹⁷² See Nancy R. Mudrick et al., *Can disability accommodation needs stored in electronic health records help providers prepare for patient visits? A qualitative study*, 20 BMC HEALTH SERVS. RSCH. 958 (2020), https://dredf.org/wp-content/uploads/2020/10/Mudrick_et_al-2020-BMC_Health_Services_Research.pdf.

¹⁷³ See Yee & Breslin, *supra* note 170, at 3.

¹⁷⁴ See Lacey Hartman & Karen Turner, State Health Access & Data Assistance Ctr. (SHADAC), Medicaid & CHIP Payment & Access Com'n. (MACPAC), *Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity* (Sept. 14, 2023), <https://www.macpac.gov/wp-content/uploads/2023/10/Federal-Survey-Sample-Size-Analysis-Disability-Language-and-Sexual-Orientation-and-Gender-Identity.pdf>; Yee et al., *supra* note 51, at 10.

¹⁷⁵ For detailed discussion on selecting a core set of demographic disability status measures, see Daniel Mont et al., *Harmonizing Disability Data To Improve Disability Research & Policy*, 41 HEALTH AFFS. 1442 (Oct. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00479>. For guidelines on implementing and realizing the potential of disability data collection, see



those who are minors or incapacitated) will help ensure covered entities have effective language access policies and procedures in place to meet their needs. This action has the potential to improve access to care for both people with disabilities and people with limited English proficiency, another underserved population that disproportionately experiences barriers to care as a result of poor communication and accessibility planning by health care entities.

We recommend HHS adopt a civil rights data collection requirement within this Proposed Rule that will require recipients to include disability and functional status questions on enrollment, application, and intake forms, research studies, surveys, and anywhere other demographic information may be requested.¹⁷⁶ We strongly recommend HHS implement this disability data collection measure while continuing to test additional measures for type, duration, and complexity of disability.¹⁷⁷ Simultaneously with adopting these measures on administrative data instruments, HHS should create a system of reporting, monitoring, and analysis of the resulting data that allows for its programs and stakeholders to deepen their understanding of people with disabilities and people at the intersections of multiple demographic characteristics that experience known barriers to health care and access.

Conclusion

We have included numerous citations to supporting research, including direct links to the research. We direct HHS to each of the materials we have cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal

Megan A. Morris et al., *Healthcare Equity Requires Standardized Disability Data in the EHR*, HEALTH AFFS. FOREFRONT (Oct. 27, 2022),

<https://www.healthaffairs.org/content/forefront/healthcare-equity-requires-standardized-disability-data-ehr>.

As a model, HHS can also look to the recently adopted HHS SOGI Data Action Plan, which provides guidelines for when HHS should include demographic measures on sexual orientation and gender identity in its data instruments. The SOGI Data Action Plan, for example, provides that HHS should add SOGI measures where the data instrument captures demographic information unrelated to program eligibility or compliance, and a plan should be created to include SOGI measures on current application and enrollment materials.

¹⁷⁷ See Jean P. Hall et al., *Comparing Measures of Functional Difficulty With Self-Identified Disability: Implications for Health Policy*, 41 HEALTH AFFS. 1433 (Oct. 2022),

<https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00395?> (noting that the current standards used by HHS “miss many people with mental and chronic illnesses, as well as some with other conditions”).



administrative record for purposes of the Administrative Procedure Act. If HHS is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.

Thank you for the opportunity to comment on these critical updates to § 504 regulations. We thank HHS leadership and the Office for Civil Rights for your diligent efforts to make these necessary changes, and we encourage swift adoption of a Final Rule. If you have any questions or concerns, please feel free to contact me at lav@healthlaw.org.

Sincerely,

A handwritten signature in black ink, appearing to read "Jennifer Lav", with a stylized flourish at the end.

Jennifer Lav
Senior Attorney