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

Submitted via Regulations.gov

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

Dear Director Fontes Rainer:

The over 70 undersigned organizations fight to advance sexual and reproductive health, rights, and justice and gender justice across the United States (U.S.). We write to express our strong support for the U.S. Department of Health and Human Services' (HHS) proposed rule, "Nondiscrimination on the Basis of Disability in Health and Human Services Programs or Activities" (Proposed Rule).¹ As the first update to § 504 regulations since 1977, the Proposed Rule is long overdue and sorely needed to clarify and strengthen protections against the pervasive health care discrimination disabled people experience,² especially disabled women and gender-expansive people of color.³

Disabled women and gender-expansive people—including disabled people of color, disabled immigrants, disabled LGBTQIA+ people, and other disabled people who experience multiple forms of marginalization—will especially benefit from increased protections under § 504 and

² Overall, the disability community has reclaimed identity-first language (i.e., "disabled") to

acknowledge disability as a critical part of identity in which to take pride. However, not all members of the disability community prefer identity-first language. Others may prefer person-first language (i.e., "person with a disability"). Preferences may also vary by disability. This comment uses identity-first and person-first language interchangeably. However, we will always honor the language a disabled person chooses for themselves. ³ We recognize that barriers to sexual and reproductive health care access affect people of all gender identities.

¹ Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 88 Fed. Reg. 63392 (proposed Sep. 14, 2023) (to be codified at 45 C.F.R. pt. 84) (hereinafter "Proposed Rule").

Accordingly, we use gender-inclusive language in our analysis (e.g., people, or women and gender-expansive people, the latter of which is an umbrella term that describes people who expand notions of gender expression and identity beyond perceived or expected societal gender norms, such as transgender and nonbinary people), except when we are referencing data and research that focus on cisgender women. More inclusive research is needed. Nat'l P'ship for Women & Families & Autistic Self Advocacy Network, *Access, Autonomy, and Dignity: Abortion Care for People with Disabilities* (Sep. 2021), <u>https://nationalpartnership.org/wp-content/uploads/2023/02/reprodisability-abortion.pdf</u>.

updates to severely outdated regulations. Women are more likely than men to have a disability, according to Census Bureau data.⁴ There are 36 million women with disabilities in the United States, a number that continues to grow.⁵ Indigenous and Black adults are also more likely to have a disability.⁶ Members of the LGBTQIA+ community are disproportionately disabled,⁷ particularly transgender people.⁸ We commend HHS for the special attention paid to concerns that have continued to impact health care access and economic security for disabled women and gender-expansive people. We urge you to incorporate our recommendations and finalize these rules as soon as possible so disabled people can benefit from the clarity that these rules provide.

I. Definitions (§ 84.4)

We commend HHS for removing the term "handicapped" from these regulations. This use of terminology is outdated, and it has not been consistent with the statutory language of the Rehabilitation Act since the early 1990s.⁹ We also commend HHS for its recognition in the preamble that, consistent with *Williams v. Kincaid*, gender dysphoria may qualify as a disability under § 504.¹⁰ As courts have recognized in cases like *Kincaid*, gender dysphoria is distinct from "gender identity disorders" and so not encompassed by the exclusion of the latter from the definition of disability. We are concerned, however, that the regulatory language reiterates the exclusion without the qualification that it does not reach gender dysphoria. In order to avoid confusion, we recommend that HHS add the following rule of construction in § 84.4(g):

Gender dysphoria is not included in the scope of "gender identity disorders" or other conditions listed in paragraph (g)(1)(a) of this section.

Additionally, we recommend that HHS recognize the nuanced ways in which variations in sex characteristics, including a range of intersex variations, may fall under § 504, as well as provide examples of prohibited discrimination on this basis. Some people with intersex variations experience "actual impairments" if those variations cause physical conditions that substantially limit the bodily functions of one or more organ systems, including the endocrine system,

https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00500.

⁴ U.S. Census Bureau, *American Community Survey 1-Year Estimates (Table S1810: Disability Characteristics)* (Sep. 2022), <u>https://data.census.gov/table?q=disability&tid=ACSST1Y2021.S1810</u>.

⁵ Ctrs. for Disease Control & Prevention, *Disability & Health Information for Women with Disabilities* (Sep. 16, 2020), <u>https://www.cdc.gov/ncbddd/disabilityandhealth/women.html</u>.

 ⁶ Ctrs. for Disease Control & Prevention, *Adults with Disabilities: Ethnicity and Race* (Sep. 16, 2020), <u>https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html</u>.
 ⁷ Movement Advancement Project, *LGBT People with Disabilities* (Jul. 2019), https://www.lgbtmap.org/file/LGBT-

⁷ Movement Advancement Project, *LGBT People with Disabilities* (Jul. 2019), <u>https://www.lgbtmap.org/file/LGBT-</u> <u>PeopleWith-Disabilities.pdf</u>.

⁸ Madeline Smith-Johnson, *Transgender Adults Have Higher Rates Of Disability Than Their Cisgender Counterparts*, 41 HEALTH AFFAIRS 1470 (Oct. 2022),

⁹ Rehabilitation Act Amendments of 1992, Pub. L. No. 102-693, 104 Stat. 1344 (1992).

¹⁰ Proposed Rule, 88 Fed. Reg. at 63464.

genitourinary system, and reproductive system.¹¹ There are many types of intersex variations that may or may not rise to the level of disrupting major bodily functions of an individual; whether or not a particular variation has an impact on an individual's daily life, it may nevertheless qualify as a disability under § 504's expansive definition.¹² Additionally, whether or not a particular variation has an impact on an individual's daily life, it may also qualify as a disability under § 504's "regarded as" prong.

II. Medical Treatment (§ 84.56)

A. Denial of medical treatment (§ 84.56(b)(1))

We strongly support the Department's inclusion of proposed § 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. We commend HHS for recognizing that disabled patients are more likely to experience biases and discrimination in medical treatment.¹³ These inequities are even more likely for disabled women, disabled Black, Indigenous, Latine, Asian American, Pacific Islander, and other people of color, disabled immigrants, and disabled LGBTQIA+ people, all of whom face higher rates of discrimination by health care providers.¹⁴

Failure to provide all appropriate and recommended clinical and preventive services has a significant economic impact on disabled people, particularly disabled women of color. When health concerns are not addressed early, there are often additional costs for avoidable

¹² See InterACT Advocates for Intersex Youth, *supra* note 11; *see also, e.g., 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. North Carolina Dep't of Pub. Safety*, 2023 U.S. Dist. LEXIS 8240 (W.D.N.C. Jan. 18, 2023) (determining Plaintiff had alleged ADA violations based on intersex status).

¹⁴ NPR, *Why Are Women's Health Concerns Dismissed So Often?*, NPR (Jan. 4, 2023), https://www.npr.org/2023/01/04/1146931012/why-are-womens-health-concerns-dismissed-so-often; Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018), https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/the-state-of-healthcare-in-theunited-states/racial-disparities-in-health-care; Caroline Medina & Lindsay Mahowald, Ctr. for Am. Progress, *Advancing Health Care Nondiscrimination Protections for LGBTQI+ Communities* (Sep. 8, 2022), https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqicommunities.

¹¹ See InterACT Advocates for Intersex Youth, Intersex Variations Glossary (Oct. 2022), https://interactadvocates.org/intersex-definitions/; see also 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 Id.; Gina Kolata, These Doctors Admit They Don't Want Patients with Disabilities, N.Y. TIMES Oct. 19, 2022), https://www.nytimes.com/2022/10/19/health/doctors-patients-disabilities.html.

complications and chronic condition management.¹⁵ This inadequate medical care also increases risk of death and has a negative impact on health outcomes.¹⁶ Poor health is also associated with increased job loss and employment,¹⁷ further impacting the economic wellbeing of disabled people.

Disability biases, judgements that an individual will be a burden on others due to their disability, and beliefs that a disabled person's life is not worth living are significantly harmful in many contexts, including the following:

Abortion. The proposed regulatory text at § 84.56(b)(1) will help fight denials of abortion care on the basis of bias or stereotypes related to an individual's disability, which disproportionately affect disabled women and gender-expansive people of color.¹⁸ Being denied abortion care can be especially dangerous for people with disabilities, who have an eleven times greater risk of maternal mortality. Moreover, given that people with disabilities are at three times greater risk of experiencing sexual assault than their nondisabled counterparts, being denied abortion care can further compound the trauma and harms from the assault.¹⁹ Nevertheless, disabled people have long faced disproportionate abortion barriers²⁰—barriers that have only increased following the U.S. Supreme Court's incorrect and harmful decision to overturn the constitutional right to abortion in *Dobbs v. Jackson Women's Health Organization*.²¹ Because of pervasive ableism and resulting biases and stereotypes, many providers do not view people with disabilities, as "competent"

¹⁵ Susan Levine et al., *Health Care Industry Insights: Why the Use of Preventive Services Is Still Low*, 16 PREVENTING CHRONIC DISEASE 180625 (Mar. 14, 2019), <u>https://www.cdc.gov/pcd/issues/2019/18_0625.htm</u>; P. L. Yong, et al. (eds.), Inst. of Medicine, *The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary* (2010), <u>https://www.ncbi.nlm.nih.gov/books/NBK53914</u>. ¹⁶ *Id*.

¹⁷ Larisa Antonisse & Rachel Garfield, Kaiser Family Found., *The Relationship Between Work and Health: Findings from a Literature Review* (Aug. 7, 2018), <u>https://www.kff.org/medicaid/issue-brief/the-relationship-between-work-and-health-findings-from-a-literature-review</u>.

¹⁸ See, e.g., Shruti Rajkumar, *With Roe v. Wade Overturned, Disabled People Reflect on How it Will Impact Them*, NPR (Jun. 25, 2022), <u>https://www.npr.org/2022/06/25/1107151162/abortion-roe-v-wade-overturned-disabled-people-reflect-how-it-will-impact-them</u> (discussing an abortion denial on the basis of a Black woman's spinal cord injury).

¹⁹ *Id.*; *NIH Study Suggests Women with Disabilities Have Higher Risk of Birth Complications and Death*, NIH (Dec. 15, 2021), <u>https://www.nih.gov/news-events/news-releases/nih-study-suggests-women-disabilities-have-higher-risk-birth-complications-death</u>.

²⁰ 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 Law Prog., *Fostering Equitable Access to Abortion Coverage: Reversing the Hyde Amendment* (Mar. 25, 2021), <u>https://healthlaw.org/resource/fostering-equitable-access-to-abortion-coverage-reversing-the-hyde-amendment/</u>.

²¹ 142 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), <u>https://time.com/6248104/abortion-access-people-with-disabilities/</u>.

to decide whether to continue their pregnancies or have an abortion, and will accordingly deny or limit abortion access.²²

Post-Roe Access to Care for Chronic Health 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 pregnancy) medications that help manage chronic health conditions, such as rheumatoid arthritis, lupus, cluster headaches, endometriosis, and Ehlers-Danlos Syndrome. Some pharmacies—both within and beyond states that ban abortion—have refused to fill prescriptions or are requiring that people navigate onerous red tape before they can access their medications.²³ Some providers have refused to prescribe or refill medications that can end or cause complications to hypothetical pregnancies, even when the individual is not and has no plan to become pregnant.²⁴ Some health insurance companies are refusing to cover essential medications for chronic health conditions.²⁵ As HHS has recognized in the context of post-*Roe* pharmacy denials, these denials of medical treatment for chronic illnesses can constitute violations of § 504.²⁶

Contraceptive Care. Providers routinely do not offer people with disabilities culturally competent, comprehensive, and empowering contraceptive counseling and care that is free from

https://www.businessinsider.com/roe-v-wade-autoimmune-patients-collateral-damage-of-abortion-ban-2022-7. ²⁴ See, e.g., Rebecca Flood, Anger as Woman Denied 'Abortifacient' Medication After Roe v. Wade Ruling,

NEWSWEEK (Jul. 4, 2022), <u>https://www.newsweek.com/anger-woman-denied-abortifacient-medication-roe-v-wade-abortion-1721428</u>; Liz Plank, *Abortion Bans are Stopping These Women from Getting Medication for their Chronic Illness*, MSNBC (Jul. 11, 2022), <u>https://www.msnbc.com/opinion/msnbc-opinion/post-roe-abortions-aren-t-only-healthcare-being-denied-women-n1296928</u>; Ellen Matloff, *One Year After Dobbs Decision, Women Blocked from Meds for Conditions Unrelated to Abortion*, FORBES (Jun. 23, 2023),

²⁵ See Plank, supra note 23.

²² Nat'l P'ship for Women & Families & Autistic Self Advocacy Network, *supra* note 3 at 12–13; Marissa Ditkowsky, Nat'l P'ship for Women & Families, *Disabled People Face Renewed Threats to Autonomy after* Dobbs *Decision* (Jul. 18, 2023), <u>https://nationalpartnership.org/disabled-people-face-renewed-threats-to-autonomy-after-dobbs-decision/</u>.

²³ See, e.g., Rose Horowitch, State Abortion Bans Prevent Women from Getting Essential Medication, REUTERS (Jul. 14, 2022), <u>https://www.reuters.com/world/us/state-abortion-bans-prevent-women-getting-essential-medication-2022-07-14/</u>; 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.forbes.com/sites/ellenmatloff/2023/06/23/one-year-after-dobbs-decision-women-blocked-from-medsfor-conditions-unrelated-to-abortion/?sh=72160d7b3277; Kylie Cheung, *Woman with Severe Chronic Pain Was Denied Medication for Being 'Childbearing Age'*, JEZEBEL (Sep. 22, 2022), <u>https://jezebel.com/woman-with-severechronic-pain-was-denied-medication-fo-1849569187</u>.

²⁶ See, e.g., Dep't of Health & Human Servs., *Guidance to Nation's Retail Pharmacies: Obligations Under Federal Civil Rights Laws to Ensure Nondiscriminatory Access to Health Care at Pharmacies* (rev. Sep. 29, 2023), https://www.hhs.gov/civil-rights/for-individuals/special-topics/reproductive-healthcare/pharmacies-guidance/index.html.

coercion. Moreover, providers often fail to offer sufficient and complete information about available contraceptive options or minimize or deny contraception requests by disabled people.²⁷ These denials of and limitations on medical treatment, including counseling, often result from providers' discriminatory biases and stereotypes about people with disabilities' sexual activity (e.g., believing that people with disabilities are asexual or hypersexual) or their ability to parent.²⁸ This discrimination is exacerbated for disabled Black, Indigenous, and Latine people; Asian Americans and Pacific Islanders; and other people of color, LGBTQIA+ people, and immigrants, who are burdened with the compounding effects of intersectional discrimination.²⁹

Assisted Reproduction. Far too often, providers deny or limit access to assisted reproductive technology (ART) for people with disabilities.³⁰ Discriminatory assumptions about parenting ability or eugenic fears that children will also be disabled often underpin providers' decisions to not refer patients to fertility therapy.³¹ These denials are also often based on discriminatory beliefs that if a person with disabilities has children, they or their children will become a burden on society.³² We encourage HHS to include reference to discrimination in ART treatment as an example of prohibited conduct in the preamble to the Final Rule.

²⁷ Id.

²⁸ *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.

²⁹ 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-Rublee, Ctr. for 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), <u>https://nwlc.org/wp-content/uploads/2017/04/Immigrant-Rights-and-Reproductive-Justice.pdf</u>; *see* Nat'l P'ship for Women & Families & Autistic Self Advocacy Network, *supra* note 3.

³⁰ Liz McCaman Taylor et al., Nat'l Health Law Prog., *NHeLP Principles on Assisted Reproduction* (Sep. 2021), <u>https://healthlaw.org/nhelp-principles-on-assisted-reproduction/</u>.

³¹ Anita Silvers et al., *Reproductive Rights and Access to Reproductive Services for Women with Disabilities*, 17 AMA J. ETHICS 433 (Apr. 2016), <u>https://journalofethics.ama-assn.org/article/reproductive-rights-and-access-reproductive-services-women-disabilities/2016-04</u>.

Chronic Pain. Women—who are substantially more likely to experience chronic pain³³ are more likely to have their pain dismissed by a provider. In a 2019 HealthyWomen survey of women who experience chronic pain, 36 percent of respondents said they did not believe that their health care providers took their pain seriously.³⁴ Women of color, particularly Black women, are more likely to find their pain dismissed by providers.³⁵ For example, one study found that 45 percent of Black women between the ages of 18 and 49 said they have encountered health providers who did not take their pain seriously.³⁶ LGBTQIA+ people are also likely to encounter stigma and discrimination when seeking medical care for their chronic pain.³⁷ We recommend that the preamble include a more in-depth look at the role gender, race, LGBTQIA+ status, and disability play in the experience of dismissal of pain symptoms by providers as well as the pervasive issue of medical gaslighting.

B. Denial of treatment for a separate symptom or condition (§ 84.56(b)(2))

We support the Department's inclusion of proposed § 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 nondisabled individual. We ask that the Department clarify and emphasize the broad scope of circumstances that operate as denials and/or limitations of medical treatment in the preamble to its Final Rule. This provision will needfully strengthen safeguards for the health care rights of people with disabilities in a sexual and reproductive health context and beyond. For example:

Care for Conditions or Symptoms Separate from HIV Status. Due to painful stigma and discrimination, people living with HIV are often denied care. A 2010 Lambda Legal survey found that 19 percent of respondents with HIV reported being denied care based on their HIV

³³ Int'l Ass'n for the Study of Pain, *Pain in Women* (accessed Oct. 26, 2023), <u>https://www.iasp-pain.org/advocacy/global-year/pain-in-women/#:~:text=Chronic%20pain%20 affects%20a%20 higher,longer%20lasting%20pain%20than%20men</u>.

³⁴ HealthWomen, *Executive Summary of HealthyWomen's Chronic Pain Survey* (2019), <u>https://roar-assets-auto.rbl.ms/documents/6876/Chronic%20Pain%20Survey.pdf</u>.

³⁵ See, e.g., Vidya Rao, 'You Are Not Listening to Me': Black Women on Pain and Implicit Bias in Medicine, TODAY (Jul. 27, 2020), <u>https://www.today.com/health/implicit-bias-medicine-how-it-hurts-black-women-t187866</u>.

³⁶ Cary Funk, Pew Rsch. Ctr., *Black Americans' Views of and Engagement With Science* (Apr. 7, 2022), https://www.pewresearch.org/science/2022/04/07/black-americans-views-of-and-engagement-with-science.

³⁷ See e.g., Alaa Abd-Elsayed et al., *Disparities in the Treatment of the LGBTQ Population in Chronic Pain Management*, 14 J. OF PAIN RESEARCH 3623 (Nov. 30, 2021), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8646952.

status.³⁸ 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.³⁹ The woman sought home-health services because she is unable to walk and needs assistance to leave her bed due to a condition that is separate from her HIV status.

Preventive Screenings for Sexually Transmitted Infections (STI) and Gynecological and Breast 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 a separate STI or gynecological (e.g., cervical, endometrial) or breast cancers.⁴⁰ While some of these inequities may be attributed to a lack of accessible medical diagnostic equipment, there is also evidence that providers are less likely to offer disabled individuals these screening services.⁴¹ This is often due to ableist assumptions regarding the sexual and reproductive health needs, sexual activity, decision-making and parenting abilities, and risks of people with disabilities.⁴² 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 percent vs. 2.2 percent) and cervical cancer (0.9 percent vs. 0.6 percent) among people with disabilities compared to people without disabilities.⁴³

⁴⁰ 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/; Erin A. Brennand & Alan Santinele Martino, *Disability is Associated with Sexually Transmitted Infection: Severity and Female Sex are Important Risk Factors*, 31 CANADIAN J. HUM. SEXUALITY 91 (2022), https://www.utpjournals.press/doi/full/10.3138/cjhs.2021-0053?role=tab; Elizabeth K. Schmidt et al., *Sexually Transmitted Infections in Privately Insured Adults with Intellectual and Developmental Disabilities*, 8 J. COMPARATIVE EFFECTIVENESS RSCH. 599 (2019), https://becarispublishing.com/doi/10.2217/cer-2019-0011.

³⁸ Lambda Legal, When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People with HIV (2010), www.lambdalegal.org/health-care-report.

³⁹ Josh Bakan, *Woman with HIV Denied Care By Burlington Co. Home-Health Services: Feds*, PATCH (Aug. 30, 2023), <u>https://patch.com/new-jersey/moorestown/woman-hiv-denied-care-burlington-co-home-health-service-feds</u>.

⁴¹ E.g., C. Brooke Steele et al., *Prevalence of Cancer Screening Among Adults with Disabilities*, 14 PREVENTING CHRONIC DISEASE 1 (Jan. 2017), <u>http://dx.doi.org/10.5888/pcd14.160312</u>.

 ⁴² See, e.g., Kenneth Robey et al., *Implicit Infantilizing Attitudes About Disability*, 18 J. DEVELOPMENTAL &
 PHYSICAL DISABILITIES 441 (Sept. 2006), <u>https://doi.org/10.1007/s10882-006-9027-3</u>; Maureen Milligan & Aldred Neufeldt, *The Myth of Asexuality: A Survey of Social and Empirical Evidence*, 19 SEXUALITY & DISABILITY 91 (Jun. 2001), <u>https://doi.org/10.1023/A:1010621705591</u>.

⁴³ Iezzoni et al., *supra* note 40.

These disability-based denials and limitations on preventive screenings compound inequities in access to care faced by people of color. For example, denials of and limitations on screening for mammograms are especially dangerous for Black women, who have a 40 percent higher breast cancer mortality rate than non-Hispanic white women, and Indigenous women, who are 17 percent less likely to be diagnosed with breast cancer than non-Hispanic white women but 4 percent more likely to die from the condition.⁴⁴ 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.⁴⁵ Black women are 30 percent more likely to die from endometrial cancer, than non-Hispanic white women.⁴⁶ Disability-based denials and limitations on access to preventive care compound these racial inequities.

Gender-Affirming Health Care. Gender-affirming care is critical and life-saving for many transgender and non-binary people, including many disabled people.⁴⁷ Too often, however, people face barriers to getting the full scope of care that they need—barriers that have been exacerbated by the onslaught of state legislative attacks on gender-affirming care. These barriers are particularly pronounced for disabled transgender and non-binary people. Many providers have been reluctant to offer gender-affirming care to disabled people—particularly those with intellectual, developmental, or mental health disabilities—based on assumptions that they are less capable of understanding or providing consent to these services.⁴⁸ In some cases, providers have imposed more stringent prerequisites for disabled people seeking this care; in others, they have imposed requirements that are impossible for some disabled people to meet, like by demanding that a chronic disability has been "cured" before the person is eligible to receive

stis/#:~:text=According%20to%20the%20CDC%2C%20in%202019%2C%20overall%20STI%20rates%3A,times%20that%20of%20White%20people.

⁴⁴ Sandy McDowell, Am. Cancer Soc'y, *Breast Cancer Death Rates are Highest for Black Women—Again*, (Oct. 3, 2022), <u>https://www.cancer.org/research/acs-research-news/breast-cancer-death-rates-are-highest-for-black-women-again.html</u>.

⁴⁵ Med. Inst. for Sexual Health, *Racial/Ethnic Disparities and STIs* (last visited Nov. 3, 2023), <u>https://www.medinstitute.org/racial-ethnic-disparities-and-</u>

⁴⁶ 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), <u>https://www.ajpmonline.org/article/S0749-</u>3797(23)00202-

^{7/}fulltext#:~:text=Racial%20disparities%20in%20cervical%20cancer,than%20non%2DHispanic%20White%20wo men; Emily Ko & Daniel Saris, *Racial Disparities in Endometrial Cancer Mortality* (May 23, 2022), https://ldi.upenn.edu/our-work/research-updates/racial-disparities-in-endometrial-cancer-mortality/.

⁴⁷ See, e.g., Jack Turban, *The Evidence for Trans Youth Gender-Affirming Medical Care*, PSYCHOLOGY TODAY (Jan. 24, 2022), <u>https://www.psychologytoday.com/us/blog/political-minds/202201/the-evidence-trans-youth-gender-affirming-medical-care</u>.

⁴⁸ See, e.g., Orion Rummler & Sara Luterman, Anti-Trans Laws Are Targeting Autistic Youth and Those With Mental Health Conditions, THE 19TH (May 30, 2023), https://19thnews.org/2023/05/trans-laws-autistic-youth-mental-health.

gender-affirming care.⁴⁹ We have also received feedback that some providers have also been reluctant to offer gender-affirming care to people with certain physical disabilities because of an unwillingness to modify the treatment to accommodate the individual's disability-related needs. We ask HHS to clarify in its preamble that such denials of gender-affirming care based on disability status may be a violation of § 504.

C. Provision of medical treatment (§ 84.56(b)(3))

We strongly support Proposed Rule § 84.56(b)(3), which would prohibit the discriminatory provision of medical treatment to individuals with disabilities. We are grateful that HHS recognized that the discriminatory forced and coercive sterilization of people with disabilities, which is rooted in the legacy of eugenics, remains pervasive to this day.⁵⁰ This ugly legacy strips people with disabilities of autonomy over their reproduction, families, and lives. Forced and coercive sterilization disproportionately harms women with intellectual and developmental disabilities and Black and brown disabled women.⁵¹ Even today, 31 states and Washington, D.C. explicitly allow the forced sterilization of disabled people.⁵² HHS' proposed regulatory text would help clarify federal protections against the discriminatory provision of sterilization to individuals with disabilities.⁵³ However, as we discuss below in our analysis of Proposed Rule § 84.56(c)(2)(ii), we ask that HHS go further to clarify protections against providers' discriminatory consent-seeking practices in its forthcoming Final Rule and subsequent guidance.

Additionally, we are concerned that providers who view disabled people as "hypersexual" or who have ingrained biases related to disabled people's ability to parent may urge them to use contraception or a contraceptive method or specific medication they do not want. For example, in addition to pressuring disabled individuals towards sterilization, health care providers may also push long-acting reversible contraception (LARCs) or other forms of contraception to encourage disabled people to avoid pregnancy. The same assumptions that have undergirded forced sterilization and eugenics in Black, brown, and disabled communities also often fuel this discriminatory practice. We encourage HHS to add language in the preamble recognizing that providers who pressure or coerce an individual to use LARCs or other forms of contraception based on their disability may be violating § 504, as do providers who deny access to contraceptives based on an individual's disability.

⁵¹ Nat'l Women's L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 50, at 8. ⁵² *Id.* at 15.

⁴⁹ See *id*.

⁵⁰ Proposed Rule, 88 Fed. Reg. at 63406; Nat'l Women's L. Ctr. & Autistic Women & Nonbinary Network, *Forced Sterilization of Disabled People in the U.S.* (Jan. 2022), <u>https://nwlc.org/resource/forced-sterilization-of-disabled-people-in-the-united-states/</u>; Paola Alonso, TX Women's U., *Autonomy Revoked: The Forced Sterilization of Women of Color in 20th Century America* 10 (2020), <u>https://twu.edu/media/documents/history-government/Autonomy-Revoked-The-Forced-Sterilization-of-Women-of-Color-in-20th-Century-America.pdf</u>.

⁵³ Id.

D. Consent (§ 84.56(c)(2)(ii))

We support Proposed Rule § 84.56(c)(2)(ii), which helps to clarify § 504's protections against discriminatory consent-seeking practices. This provision is badly needed to address recipients' practices that beget coercive or forced sexual and reproductive health care, including irreversible medical procedures, and resulting health inequities and interconnected reproductive oppression. HHS should clarify how these practices can violate this section in the preamble to the Final Rule. Moreover, through guardianship and other substituted consent arrangements, some disabled people can be forced to continue pregnancies or have abortions against their will. Denial of legal capacity through guardianship can also restrict people's right to this care. When a provider requires a disabled person to be subjected to guardianship as a precondition for providing a service, that may constitute a discriminatory denial of or limitation on medical treatment. Similarly, a provider's refusal to treat a disabled person without a guardian may constitute discrimination.

When a recipient has questions about a disabled individual's understanding of medical treatment options, they should make reasonable modifications. 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) in this context.⁵⁴ While we appreciate this section's emphasis on informed consent, it should be strengthened by cross-referencing and underscoring a health care provider's obligations to provide reasonable modifications in the decision-making process. This may include, for example, modifications to sterilization consent policies to allow a designated support person to be present to help facilitate effective communication⁵⁵ and/or help a person with a disability decide on the best course of treatment; the use of a supported-decision making arrangement;⁵⁶ or the presentation of information about medical treatment decisions in a way that is accessible and readily understandable to the person with a disability.

Amid increasing reproductive oppression across the United States, HHS has a critical role to play in elevating the importance of reasonable modifications in the context of consent. This is especially important in the context of sterilization and other sexual and reproductive health care, where there is great risk of coercion and a long and pervasive history of recipients riding slipshod over individuals' right to consent to or decline treatment.⁵⁷ Specifically, the preamble

⁵⁴ Proposed Rule, 88 Fed. Reg. at 63474.

⁵⁵ We note that allowing the presence of a support person to help facilitate communication does not negate a recipient's obligation to provide other reasonable modifications such as a sign language interpreter.
⁵⁶ See Proposed Rule, 88 Fed. Reg. at 63474.

⁵⁷ Emily DiMatteo et al., Ctr. for Am. Progress, *Reproductive Justice for Disabled Women: Ending Systemic Discrimination* (Apr. 13, 2022), <u>https://www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination</u>.

should clarify that when a provider or other recipient discriminatorily pursues a court order to authorize sterilization or other reproductive decisions rather than seeking a disabled patient's informed consent, they may violate § 504. We also ask HHS to clarify that state laws, such as laws explicitly sanctioning forced sterilization of disabled people, do not provide a defense to a provider who has otherwise violated § 504. Centering nondiscrimination in medical treatment means that recipients should move beyond pursuing and initiating court orders and substituted decision-making models such as guardianship that underlie coercive and forced sterilization, which rest on discriminatory, paternalistic notions about whether disabled people should be allowed to parent or self-determine their reproductive futures. The preamble should direct recipients to instead make reasonable modifications to decision-making processes that center and support a disabled person's self-determination in medical treatment, such as supported decisionmaking. People with disabilities can make their own decisions about sterilization, abortions, pregnancy and related care, gender-affirming health care, and other medical treatments when provided with appropriate, accessible supports tailored to their needs.⁵⁸ In particular, we urge HHS to encourage the use of supported decision-making as a reasonable modification that can empower disabled individuals to decide which medical treatments are right for them. HHS should stress in the preamble to this section of the Final Rule that failure to offer reasonable modifications may violate § 504.

Moreover, we ask that, following the promulgation of the Final Rule, HHS issue guidance to covered health care providers and entities promoting the use of supported decision-making and other reasonable modifications 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.

We also recommend that HHS specifically name nonconsensual surgeries on people with intersex variations that constitute disabilities that they would not provide to a non-disabled intersex person as a potential violation of § 504. People with intersex variations that qualify as disabilities are often forced to undergo medically unnecessary genital surgeries and gonadectomies when they are too young to assent, often in the first two years of life.⁵⁹ Providers often pursue these procedures based on discriminatory beliefs that individuals' bodies should conform with stereotypes associated with their initial gender assignment.⁶⁰ These procedures can have lifelong, irreversible consequences on an individual's reproductive and sexual function—including permanent sterilization—and their overall health and wellbeing, potentially *creating* an

⁵⁸ Nat'l Women's L. Ctr. & Autistic Women & Nonbinary Network, *supra* note 50 at 38.

⁵⁹ See, e.g., Human Rights Watch, "I Want to be Like Nature Made Me": Medically Unnecessary Surgeries on Intersex Children in the US (2017), <u>https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us</u>.

actual impairment where none existed before.⁶¹ Nearly all providers would decline to perform such procedures on a non-intersex young child due to the serious risks of harm coupled with a lack of capacity to consent. But for children with intersex variations, providers apply a different standard of consent when the child is intersex, often disregarding standard protocols related to consent for sterilization.⁶² Such practices may constitute discrimination based on disability—specifically, differential treatment based on variations in sex characteristics.

III. Child Welfare System (§ 84.60)

Disabled people—particularly disabled women—face routine attacks on their reproductive freedom and decisions to parent, including through adoption, fostering, or other means. There is a misconception, based entirely on biases and ableist assumptions, that disabled people may be unable or unfit to parent. Parents with disabilities are referred to child welfare at higher rates, and once referred, the parental rights of parents with disabilities are disproportionately terminated.⁶³ About 35 states include disability as grounds for termination of parental rights.⁶⁴ In every state, a family court can consider the disability of the parent in making a determination about the best interest of the child, such as in a removal, custody, or placement hearing.⁶⁵ Several states allow the termination of parental rights based on physical disability alone without any evidence of abuse or neglect.⁶⁶

Proposed § 84.60 addresses this discrimination, stereotyping, and bias in the child welfare system. We commend HHS for ensuring this form of discrimination is impermissible. We also commend HHS for making it clear that state welfare programs cannot fail to provide reasonable accommodations for qualified disabled parents or provide supports that would otherwise be offered to nondisabled parents.

As recipients of HHS funds, child welfare agencies have an obligation to provide the full range of supports and accommodations, including mental health services, necessary for children to remain in the least restrictive environment, preferably with their families of origin when possible. When such agencies encourage parents to relinquish custody so their children can access necessary services, they not only violate § 504 but also perpetuate a pervasive reproductive justice concern—denying disabled parents of their fundamental right to have

⁶¹ Id.

⁶² Id.

⁶³ Nat'l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 18 (Sep. 27, 2012), <u>https://ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf</u>.

⁶⁴ Nat'l Council on Disability & Christopher and Dana Reeve Foundation, *Parenting with a Disability: Know Your Rights Toolkit* 5 (May 5, 2016),

https://www.ncd.gov/sites/default/files/Documents/Final%20508_Parenting%20Toolkit_Standard_0.pdf. ⁶⁵ Id.

⁶⁶ Id.

children should they so choose.⁶⁷ While the specific examples in the "additional provisions" listed in § 84.60(b) are helpful, the provisions fail to capture the discrimination against disabled parents that may take place when child welfare systems encourage custody relinquishment to access supports via the child welfare system. We believe an additional explicit prohibition against such actions would be helpful.

IV. Value-Based Assessments (§ 84.57)

We support HHS' proposal that clarifies that when value assessments methods discounting the value of life extension for disabled people are "used 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 an aid, benefit, or service, a recipient using such value assessment methods for these purposes is in violation of § 504." The problem of discriminatory value assessments is compounded for disabled women of color and multiply marginalized disabled people who face several biases and layers of discrimination related to the perceived "burdens" they place on others. We therefore also urge HHS to reference the way race, gender, and other aspects of identity play in value assessments in the preamble.

V. Integration (§ 84.76)

We commend HHS on its efforts to codify the holding of landmark case *Olmstead v. L.C.* While *Olmstead* has been the law of the land since 1999, we believe this effort will help to clarify provider and HHS fund recipient obligations, assist with HHS enforcement, and promote sexual and reproductive health, rights, and justice and gender justice for disabled people.

VI. Web, Mobile, and Kiosk Accessibility (§§ 84.82-84.89)

Addressing web, mobile, and kiosk accessibility is also critical for the medical care, including sexual and reproductive health care, of disabled women and gender-diverse people. Blood tests and urine samples, for example, are a routine part of care during pregnancy.⁶⁸ When disabled people are unable to access these services, such as in the *Vargas v. Quest Diagnostics Clinical Laboratories, Inc.* case in the Central District of California, the lives of the pregnant person and the fetus may both be at risk.⁶⁹

⁶⁷ Nat'l Council on Disability, *supra* note 63; Nat'l P'ship for Women & Fams & Autistic Self-Advocacy Network, *supra* note 3 at 11.

⁶⁸ Am. Coll. of Obstetricians & Gynecologists, *Routine Tests During Pregnancy* (Aug. 2023), <u>https://www.acog.org/womens-health/faqs/routine-tests-during-pregnancy</u>.

⁶⁹ Statement of Interest of the United States, *Vargas v. Quest Diagnostics Clinical Lab'ys, Inc.*, No. CV198108DMGMRWX, 2021 WL 5989961 (C.D. Cal. *filed* Sep. 21, 2021).

Additionally, telehealth has increasingly become an important method of accessing abortion, especially in the aftermath of the COVID-19 pandemic, which continues to threaten the lives of many disabled people.⁷⁰ The Department's recognition of the necessity for accessible telehealth platforms is critical to ensuring that people with disabilities have access to a full range of care, including sexual and reproductive services.

VII. Medical Diagnostic Equipment (§§ 84.91-84.93)

HHS' proposed requirements for medical diagnostic equipment will help disabled people, including disabled women and disabled women of color, access the critical health care they require. Part of this care is preventive care, such as mammograms and Pap smears. A 2017 study using 2013 National Health Interview Survey data showed that disabled women were much less likely to receive Pap smears (as low as 66.1 percent) compared with nondisabled women (81.4 percent).⁷¹ Disabled women were also much less likely to have a mammogram (as low as 61.2 percent) when compared with nondisabled women (72.8 percent).⁷² Further, disabled people are more likely to be diagnosed with breast cancer at later stages⁷³ and have higher breast cancer mortality rates⁷⁴ compared with their nondisabled peers. While denials of and limitations on care contribute to this problem, so does inaccessible diagnostic equipment (e.g., exam tables, chairs, radiological equipment, and patient lifts). Inaccessible scales may also impact prenatal care. Physicians have reported sending patients in wheelchairs to supermarkets, grain elevators, zoos, or cattle processing plants to obtain their weight measure.⁷⁵ Not only is this dehumanizing, but it also delays necessary care. We urge HHS to recognize that the availability of accessible medical and diagnostic equipment is only one important part of reducing barriers to healthcare for disabled people. Providers must be trained on how to use the accessible medical and diagnostic equipment, as well as given guidance on how to interact with disabled patients in a culturally competent manner.

⁷⁰ Gabriela Weigel Amrutha Ramaswamy, Kaiser Family Found., *Medication Abortion and Telemedicine: Innovations and Barriers During the COVID-19 Emergency* (Jun. 2021), <u>https://www.kff.org/policy-</u>watch/medication-abortion-telemedicine-innovations-and-barriers-during-the-covid-19-emergency.

⁷¹ C. Brooke Steele et al., *supra* note 41.

⁷² Id.

⁷³ Richard G. Roetzheim & Thomas N. Chirikos, *Breast Cancer Detection and Outcomes in a Disability Beneficiary Population*, 13 J. HEALTH CARE FOR THE POOR AND UNDERSERVED 461 (Nov. 4, 2002), <u>https://sci-hub.se/10.1353/hpu.2010.0606</u>.

⁷⁴ Ellen P. McCarthy et al., *Disparities in Breast Cancer Treatment and Survival for Women with Disabilities*, 145 ANNALS OF INTERNAL MED. 145 (Nov. 7, 2006), <u>https://www.acpjournals.org/doi/full/10.7326/0003-4819-145-9-200611070-00005</u>.

⁷⁵ Tara Lagu et al., '*I Am Not the Doctor for You*': *Physicians' Attitudes About Caring for People with Disabilities*, 41 HEALTH AFFAIRS 1387 (Oct. 2022),

https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00475?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed.

VIII. 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 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 with an opportunity to submit copies of the studies and articles into the record.

Thank you for the opportunity to comment on these important issues. If you have further questions, please contact Ma'ayan Anafi, Senior Counsel for Health Equity and Justice at the National Women's Law Center at <u>manafi@nwlc.org</u>, Marissa Ditkowsky, Disability Economic Justice Counsel at the National Partnership for Women & Families at <u>mditkowsky@nationalpartnership.org</u>, and Madeline T. Morcelle, Senior Attorney at the National Health Law Program at <u>morcelle@healthlaw.org</u>.

Sincerely,



Religious Coalition for Reproductive Choice Indiana Legal Services Women Enabled International Guttmacher Institute Advocates for Youth Women's Rights and Empowerment Network National Pain Advocacy Center Physicians for Reproductive Health Citizens for Choice National Organization for Women Association of Asian Pacific Community Health Organizations (AAPCHO) American Humanist Association Public Justice Center Access Reproductive Justice Reproductive Freedom For All (formerly NARAL Pro-Choice America) American Association of People with Disabilities Tennessee Justice Center National Hispanic Medical Association California Pan-Ethnic Health Network Midwest Asian Health Association National Asian Pacific American Women's Forum **Reproductive Health Access Project** National Health Law Program UCSF Bixby Center for Global Reproductive Health **Caring Across Generations** Disability Rights Education and Defense Fund (DREDF) **Prevention Institute** Northwest Health Law Advocates New York Legal Assistance Group (NYLAG) The Leadership Conference on Civil and Human Rights National Association of Certified Professional Midwives Birth In Color The Network for Public Health Law U.S. Gender and Disability Justice Alliance National Hispanic Medical Association Center for Civil Justice **Community Catalyst** Jacobs Institute of Women's Health National Network to End Domestic Violence

National Disability Institute SIECUS: Sex Ed for Social Change AccessMatters Nebraska Appleseed Healthy and Free Tennessee Center for Reproductive Rights Disability Policy Consortium Ibis Reproductive Health Planned Parenthood Federation of America Southern Poverty Law Center Action Fund A Better Balance Autistic Self Advocacy Network Asian & Pacific Islander American Health Forum (APIAHF) National Asian Pacific American Women's Forum