

August 13, 2019

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

via Online Portal (www.regulations.gov)

RE: HHS-OCR-2019-0007; Nondiscrimination in Health and Health Education Programs or Activities (RIN 0945-AA11)

Dear Director Severino:

The Disability Rights Education and Defense Fund (“DREDF”) appreciates the opportunity to provide comment on the proposed rule to revise the regulations implementing Section 1557 of the Patient Protection and Affordable Care Act (“ACA”). DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives.

DREDF is gravely concerned with HHS’ proposed amendments to the Section 1557 regulations. While we appreciate that HHS seeks to reduce costs and improve health plan sustainability, these goals cannot be sought at the expense of the civil rights of health care consumers—and particularly those individuals and families who already face pervasive physical, programmatic, and attitudinal barriers in the health care context. The proposed changes to the Section 1557 regulations would significantly weaken the civil rights of already disadvantaged groups, and it will have a disproportionately harmful effect on the provision of health care for, and the health outcomes experienced by, people with disabilities. Such harms are not what Congress intended in enacting the ACA and, as a federal agency charged with promulgating regulations that are consistent with the text and purposes of the enabling statute, HHS would exceed its legally permitted scope of authority by finalizing them.

In enacting the ACA in 2010, Congress sought to ensure that all Americans, including Americans with disabilities, have equal and comprehensive access to health insurance coverage. Prior to the ACA, people with disabilities were commonly denied or terminated from health coverage,

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faced annual and lifetime benefit limits, and could not find affordable coverage.¹ Even if a disabled individual could find health insurance, it would often exclude coverage of pre-existing conditions, fail to offer essential benefits, or otherwise limit benefits based on health status or disability. With the ACA, Congress explicitly outlawed these longstanding discriminatory policies, and Section 1557 was the key to enforcing these reforms. The ACA expanded access to basic health insurance coverage; it created protections in enrollment, cost-sharing, and benefit design; and it improved the scope and quality of essential health care benefits. See 42 U.S.C. §§ 300gg-3(b)(1), 18022, 18031(c)(1)(A). Section 1557 serves as the enforcement mechanism of these equitable reforms—placing an outer limit on the permissible practices of health plans and health providers. See *id.* § 18116(a). While the ACA did not require a health plan to offer every possible service or a health provider to offer every possible accommodation, it did require them to offer certain minimum features to meet the basic needs of Americans, without excluding or limiting them from care because of their race, age, sex, or disability. In order to protect the basic civil rights of people with disabilities in health care, it is essential that Section 1557’s regulations remain fair and comprehensive.

In these comments, DREDF provides section-by-section analysis of how the proposed changes to the Section 1557 regulations would harm health care consumers and undermine the ACA’s clear objectives. While the primary focus of these comments is on the impact that the proposed rules would have on people with disabilities, in Sections IV and V, we also briefly highlight prospective impacts on other historically marginalized groups, whose identities often intersect with disability.

¹ See generally, e.g., Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act*, 36 B.C. J. L. & Soc. JUST. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J. L. ETHICS & PUB. POL’Y 235 (2014) (describing the ACA’s nondiscrimination provisions and focusing on the function of its essential health benefit requirements).

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I. SCOPE OF APPLICATION

A. Covered Entities (45 C.F.R. §§ 92.1, 92.2, 92.4, Proposed § 92.3)

DREDF strongly opposes HHS' proposal to limit the scope of covered entities under Section 1557. Regulations currently define "health program or activity" to properly cover "all [] operations" of "entit[ies] principally engaged in providing or administering health services or health insurance coverage or other health coverage." 45 C.F.R. § 92.4. Furthermore, existing rules correctly apply Section 1557 to any program or activity administered HHS, not just programs established under Title I of the ACA. *Id.* § 92.2. The Proposed Rule attempts to severely limit the scope of covered health programs and activities under these provisions, in a proposal that directly contradicts the statutory text of Section 1557 and the purposes of the ACA. HHS should refrain from narrowing the scope of the current regulations.

i. Health Insurers Are "Health Programs or Activities," For Which All Operations Are Subject to Section 1557

DREDF strongly opposes the proposal at § 92.3 to restrict the scope of Section 1557's application to health care insurers. The Proposed Rule incorrectly interprets "health programs and activities" to exclude health insurers, and it erroneously incorporates the Civil Rights Restoration Act ("CRRRA") into Section 1557. These proposed revisions are contrary to Section 1557's clear statutory language and should not be codified.

Section 1557 prohibits disability-based discrimination in "any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title [of the ACA]." 42 U.S.C. § 18116(a). HHS' 2016 interpretation of "health program or activity" to include health insurers (and, in accordance with the statutory language, to cover all of these insurers' activities if any part of their operations receives federal financial assistance) was not only appropriate, it was required by the law. The statutory language that Congress used in Section 1557 is extremely broad, covering "*any* health program or activity." Health insurers clearly have a significant role in the provision of health care, including controlling access to health care services through benefit design, utilization management, and other means. Moreover, the *primary purpose* of the ACA was to expand the availability and scope of health insurance and assist individuals in securing and enrolling in health insurance coverage. Further, the debate about the non-discrimination provisions during the passage of the ACA was specifically about discrimination in insurance. If Congress meant to exclude health insurance from the term "health program or activity"—particularly in a law that is *about* health insurance—certainly it would have made this point clear. Thus, the 2016 Final Rule's definition of health program or activity ("the provision or administration of health-related services, health-related insurance coverage, or other health-related coverage, and the provision of assistance to

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individuals in obtaining health-related services or health-related coverage”²) reflects the clear language and intent of the law.³

In the proposal at hand, HHS re-interprets “health program or activity,” concluding that an entity “principally or otherwise engaged in the business of providing health insurance shall not, by virtue of such provision, be considered to be principally engaged in the business of providing health care.” 84 Fed. Reg. at 27850, 27891. It further states that federal financial assistance to *any part* of such an entity is not sufficient to trigger coverage of the entity under Section 1557, a conclusion entirely inconsistent with its statutory language.

The only justification that HHS offers for reading health insurance out of “health care” is a reference to another federal statute (5 U.S.C. § 5371) with an entirely different purpose, which defines “health care” for purposes of that law as “direct patient-care services or services incident to direct patient care-services.” See 84 Fed. Reg. at 27850, 27863. That law, however, concerns pay rates and personnel practices for federal employees, and it uses the term “health care” simply to describe a category of federal employees who work in that sector. It would make little sense for that law to include individuals engaged in providing health insurance, as the federal government does not employ a large set of individuals to provide health insurance. Using an unrelated law with a different purpose to define health insurance largely out of the non-discrimination provisions of a law that is *about health insurance* is without foundation and inconsistent with the statute that HHS is interpreting.

Furthermore, the Proposed Rule incorrectly attempts to incorporate the CRRA directly into Section 1557. See 84 Fed. Reg. at 27846, 27850. The CRRA is a federal statute that clarifies the scope of application of Section 504, Title VI, Title IX, and the ADEA. Pub. L. 100-259, 102 Stat. 28 (Mar. 22, 1988). The CRRA predates the ACA and nothing in its text applies its provisions to future statutes. See *id.* Likewise, in enacting the ACA in 2010, Congress did not incorporate the CRRA into Section 1557, even though it had the opportunity to do so. See 42 U.S.C. § 18116(a)

Despite these clear statutory findings, HHS’ proposal attempts to incorporate the CRRA’s definition of “program or activity” receiving federal financial assistance (“FFA”) into Section 1557,

² 45 C.F.R. § 92.4. The Final Rule further specified that, for an entity “principally engaged in providing or administering health services or health insurance coverage or other health coverage” (including all health insurers), all of its operations are subject to Section 1557. *Id.*

³ HHS acknowledged in the 2016 Final Rule that there are concerns about excluding Medicare Part B from the definition of federal financial assistance. HHS Nondiscrimination in Health Programs and Activities; Final Rule, 81 Fed. Reg. 31376, 31384 (May 18, 2016) (hereinafter “2016 Final Rule”). However, because HHS determined that the Section 1557 rule was not the appropriate place to change its position on the issue, we do not raise those concerns here.

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in an attempt to limit the scope of covered operations of health insurers. The CRRA clarified that private entities are covered by relevant laws (Section 504, Title VI, and Title IX) if their programs or activities receive FFA “as a whole” or if the entity is “principally engaged in the business of providing . . . health care”⁴ HHS—now having arbitrarily defined health insurance out of “the business of providing health care”—attempts to apply a pre-ACA law, whose application to the ACA is unfounded and unnecessary, to assert that health insurers are only covered by Section 1557 to the extent that a particular operation receives FFA.

This proposal is illogical and plainly inconsistent with the statutory language of Section 1557. Congress has already answered the question of whether coverage under Section 1557 requires FFA for *part* of a program or activity or for its operations as a *whole*: it expressly stated in the statute that any health program or activity is covered if “any part” of it receives FFA. 42 U.S.C. § 18116(a). The Proposed Rule ignores this clear statutory language. There is simply no logical way to interpret Section 1557’s language to be consistent with HHS’ new interpretation.

Furthermore, to the extent that HHS relies on Section 1557’s references to the “grounds” and “enforcement mechanisms” of Section 504, Title VI, Title IX, and the ADEA in order to incorporate the CRRA, note that the U.S. Supreme Court has already held that a statute’s incorporation of another statute’s enforcement mechanisms does not necessarily incorporate its substantive law. See *CONRAIL v. Darrone*, 465 U.S. 624 (1984) (holding that Section 504’s incorporation of the “remedies, procedures, and rights” set forth in Title VI did not mean that Section 504 incorporated Title VI’s substantive limitations on actionable discrimination). The incorporation of the CRRA into Section 1557 will not withstand judicial scrutiny.

ii. All Health Programs Administered by HHS (Not Just Those Created Under ACA Title I) Are Covered Entities Under Section 1557

DREDF also objects to the proposed rules that seek to narrow the scope of Section 1557 as it applies to HHS activities and programs receiving FFA from HHS. Section 1557, by its statutory terms, applies to all health programs administered or financially supported by HHS. The Proposed Rule, as currently formulated, unlawfully narrows the departmental entities it covers. See Proposed 45 C.F.R. §§ 92.2, 92.3. It seeks to exclude a wide range of important HHS activities, including, e.g., programs administered by the Health Resources and Services Administration (“HRSA”), which support the health care workforce and improve health care for people who are geographically isolated or medically vulnerable. This proposal stands contrary to the statutory text, design, and intent of Section 1557 and the ACA.

⁴ HHS Nondiscrimination in Health and Health Education Programs or Activities; Proposed Rule, 84 Fed. Reg. 27846, 27850, 27862 (June 14, 2019) (hereinafter “2019 Proposed Rule”).

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The plain language of Section 1557, as well as the 2016 Final Rule, establishes that any health “program or activity” administered by an Executive agency is subject to the law’s provisions. 42 U.S.C. § 18116(a); 42 C.F.R. §§ 92.1, 92.2, 92.4. HHS’ new interpretation of Section 1557 impermissibly changes the word “or” to “and,” in an attempt to narrow the rule’s application to only health programs or activities administered by an Executive agency “and” created under Title I of the ACA. See 84 Fed. Reg. at 27862. This reading is inconsistent with the statute, which uses the word “or,” thereby plainly prohibiting discrimination by both programs or activities “administered by an Executive Agency” *as well as* those entities “established under” ACA Title I. If Congress had intended to limit Section 1557 to only those entities created under Title I, it would not have included the additional clause pertaining to Executive agencies.

Moreover, this proposal would produce illogical results. It would create a situation whereby recipients of FFA would be subject to Section 1557’s nondiscrimination requirements, but agencies administering or funding such programs would be exempt. For example, state Medicaid programs would be subject to Section 1557 as recipients of FFA, but the Centers for Medicare and Medicaid Services (“CMS”), which oversees these programs, would be exempt. Such an interpretation is not only inconsistent with the plain meaning of Section 1557, but also inconsistent with Section 504 and therefore likely to cause significant confusion. HHS and all of its components, including CMS, HRSA, the Centers for Disease Control and Prevention (“CDC”), and the Substance Abuse and Mental Health Services Administration (“SAMHSA”), are subject to Section 504, see 29 U.S.C. § 794; 45 C.F.R. Part 85, as well as Section 1557.

Finally, the narrowing of Section 1557’s application will have a disproportionate impact on people with disabilities, contrary to the purposes of the ACA. People with disabilities have been and continue to be systemically disadvantaged by the U.S. health system, which has fragmented funding and delivery systems, an institutional bias in its provision of long-term services and supports (that many people with disabilities rely on to live, work, attend school, and participate in their communities), and a long history of exclusion of people with disabilities from research and clinical trials, to name just a few troubling issues in a history of unequal treatment. This narrow and incorrect interpretation of Section 1557’s application to HHS programs will only serve to exacerbate these systemic discriminatory disparities. As HHS itself has stated in the context of the Section 1557 regulations, “a fundamental purpose of the ACA is to ensure that vital health care services are broadly and nondiscriminatorily available to individuals throughout the country.”⁵ This proposal certainly does not further, and indeed will undermine, this goal.

RECOMMENDATION: HHS should retain the current regulations addressing the applicability of Section 1557 in their entirety, and it should not finalize proposed 45 C.F.R. §§ 92.2, 92.3.

⁵ HHS Nondiscrimination in Health Programs and Activities; Proposed Rule, 80 Fed. Reg. 54172, 54172 (Sept. 8, 2015) (hereinafter “2015 Proposed Rule”).

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II. DISCRIMINATION GENERALLY

A. Discrimination Prohibited (45 C.F.R. § 92.101)

DREDF opposes HHS' proposal to eliminate 45 C.F.R. § 92.101. While HHS claims that it will replace this regulation with "provisions addressing Section 1557's purpose, nondiscrimination requirements, scope of application, enforcement mechanisms, relationship to other laws, and meaningful access for LEP individuals," 84 Fed Reg. at 27856, 27860, the Proposed Rule fails to incorporate important prohibitions on discrimination that are currently contained in § 92.101.

By eliminating § 92.101(b)(2), HHS deletes references to important regulatory definitions of disability discrimination. For example, the current regulation states that "Each recipient and State-based MarketplaceSM must comply with the regulation implementing Section 504, at §§ 84.4(b), 84.21 through 84.23(b), 84.31, 84.34, 84.37, 84.38, and 84.41 through 84.52(c) and 84.53 through 84.55 of this subchapter." 45 C.F.R. § 92.101(b)(2)(i). It also states that "[t]he Department, including the Federally-facilitated Marketplaces, must comply with the regulation implementing Section 504, at §§ 85.21(b), 85.41 through 85.42, and 85.44 through 85.51 of this subchapter." *Id.* § 92.101(b)(2)(ii). These cross-references clarify that covered entities have an affirmative obligation to ensure that their health care is accessible to individuals with disabilities in a myriad of ways that are not captured in other sections of the Proposed Rule.

For example, §§ 84.4(b) and 85.21(b) prohibit the following forms of disability discrimination: denying individuals with disabilities the opportunity to participate; affording unequal opportunity to participate; providing a less effective aid, benefit or service; providing different or separate aids, benefits, or services; or otherwise limiting a person with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service. These regulations also prohibit covered entities from "utiliz[ing] criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State." 45 C.F.R. §§ 84.4(b), 85.21(b).

In short, without the inclusion of § 92.101, the Proposed Rule's description of prohibited discrimination under Section 504, and thereby Section 1557, lacks established detail and is incomplete. By removing references to explanatory regulations, it injects ambiguity into Section 1557 and risks inconsistency with the discrimination actionable under Section 504.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.101 in its entirety.

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B. Discrimination Based on Association (45 C.F.R. § 92.209)

DREDF also opposes HHS' unjustified elimination of 45 C.F.R. § 92.209, which prohibits discrimination on the basis of association with a protected class. Without explanation, the Proposed Rule attempts to remove this provision. However, Congress intended Section 1557 to protect against discrimination by association, and these provisions should be retained.

In the 2016 Final Rule, HHS explained that Section 1557 does not restrict “the prohibition to discrimination based on the individual’s own race, color, national origin, age, disability or sex. Further, we noted that a prohibition on associational discrimination is consistent with longstanding interpretations of existing antidiscrimination laws, whether the basis of discrimination is a characteristic of the harmed individual or an individual who is associated with the harmed individual.” 81 Fed. Reg. at 31439.

The current regulation’s language tracks the statutory text of Title I and Title III of the Americans with Disabilities Act (“ADA”), and the regulatory language of Title II of the ADA, which protect against discrimination based on association or relationship with a person with a disability.⁶ In enacting Section 1557, Congress intended to provide at least the same protections for health care consumers. In accordance with the ADA, the current regulation at 45 C.F.R. § 92.209 recognizes that people associated with a person with a disability, who may be at risk of discrimination due to their relationship with a patient, are protected under Section 1557.

If this regulation were eliminated, then a doctor could, for example, refuse to treat an individual who has an HIV-positive partner based on unfounded fears of transmission. On similar lines, a health insurer could refuse a provider’s application to join a plan network if they choose to work with populations of individuals with chronic infectious diseases. Likewise, a hospital could refuse to treat a white patient because they have a biracial child, or it could exert pressure on a worried hearing parent with elementary sign language skills to interpret for her admitted Deaf child. Such inequitable and bigoted results are not what Congress intended in enacting the ACA.

By eliminating the regulatory provision expressly prohibiting discrimination on the basis of association, HHS will create uncertainty and confusion regarding the responsibilities of providers and the rights of people who experience discrimination. However, because HHS provides no explanation of its reasons for removing 45 C.F.R. § 92.209, we cannot adequately comment. We urge HHS to retain the current regulatory protections.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.209 in its entirety.

⁶ See 42 U.S.C. §§ 12112(b)(4) (Title I), 12182(b)(1)(E) (Title III); 28 C.F.R. § 35.130(g) (Title II).

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C. Discriminatory Benefit Design (45 C.F.R. § 92.207)

DREDF strongly opposes HHS' proposal to eliminate 45 C.F.R. § 92.207, a regulation making clear that Section 1557 prohibits covered entities from discriminating in the issuance or renewal of a health insurance policy, the coverage of a health insurance claim, cost-sharing and other coverage limitations, marketing practices, and the design of the health benefit plan. HHS' proposal to repeal this entire regulation is contrary to the text and purposes of the ACA; it would disproportionately harm people with disabilities; and it is inadequately justified in the Notice of Proposed Rulemaking ("NPRM").

In enacting the ACA, Congress intended to prohibit health insurance practices, including plan benefit designs, that discriminate on the basis of race, color, national origin, sex, age, or disability. The ACA significantly changed the health insurance industry by not only expanding access to health coverage, but also explicitly prohibiting many of the methods historically used by health insurers to minimize costs and risks. Before the ACA, the business model of health care incentivized insurers to avoid covering individuals who had high health needs or who would otherwise be costly to the plan. While there was some federal and state regulation of restrictive coverage policies, insurers still had a large array of discriminatory mechanisms at their disposal to deny enrollment, limit benefits, and impose high premiums and cost-sharing on enrollees with disabilities and pre-existing conditions.⁷ The ACA ushered in a new era for health care equity—implementing reforms to expand coverage; create protections in enrollment, cost-sharing, and benefit coverage; and improve the scope and quality of health insurance.

As an integral component of these reforms, Congress mandated comprehensive health benefit coverage and explicitly prohibited discrimination in the *content* of those plan designs. Most pertinent, it prohibited limitations or exclusions of benefits based on pre-existing conditions; mandated coverage, on a nondiscriminatory basis, of ten categories of essential health benefits ("EHBs"); and prohibited qualified health plan ("QHP") "marketing practices or benefit designs that have the effect of discouraging the enrollment in such plan by individuals with significant health needs," among other protections. 42 U.S.C. §§ 300gg-3(b)(1), 18022, 18031(c)(1)(A).

Section 1557 of the ACA is the key to enforcing these statutory mandates. Section 1557 prohibits discrimination, including discrimination in the design of a benefit package, in health programs or activities receiving federal financial assistance. *See id.* § 18116(a). By statute, it creates a private right of action for individuals to enforce their civil rights in the health care context.⁸ The scope of

⁷ *See, e.g.,* Blake, *supra* note 1; Rosenbaum et al., *supra* note 1.

⁸ *See, e.g.,* Rumble v. Fairview Health Servs., No. 14-cv-2037, 2015 WL 1197415 (D. Minn. Mar. 16, 2015) (finding that Section 1557 creates a private right of action).

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actionable discrimination under Section 1557 logically covers discrimination in enrollment, equal access to benefits, and benefit design.⁹

Recognizing this statutory requirement, HHS promulgated regulations in 2016 reiterating that Section 1557 prohibits “marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy.” 45 C.F.R. § 92.207. In guidance, it provided examples of practices that would contravene Section 1557 and this regulation. Plans that, for example, “cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities;”¹⁰ “place[e] most or all drugs that treat a specific condition on the highest cost tiers;”¹¹ or “exclude bone marrow transplants regardless of medical necessity”¹² would run afoul of Section 1557, it explained.

HHS’ 2016 regulation logically follows the letter and intent of the ACA. Without explicit acknowledgement of and a resulting prohibition on discriminatory benefit design, Section 1557’s nondiscrimination protections would be rendered illusory. By not reaching the structure of a benefit package, a health insurer could always manipulate their benefit design to elude discrimination law, despite maintaining the same discriminatory effects. For illustration, consider cancer benefits. Without the ACA reaching benefit design, a health insurer could not deny an individual with cancer enrollment in a QHP or equal access to the treatments, services, and prescription drugs the plan chooses to cover; however, it could exclude from its coverage all cancer-related surgery, chemotherapy, radiation, and post-treatment drugs. It could also limit beneficiaries to provider networks that fail to include key oncology specialists, thus avoiding coverage of the expensive treatments they may prescribe. For a person with cancer, access to a health plan would be deemed virtually meaningless in the absence of cancer-related coverage. The effect of these exclusions would be the same as an outright denial of enrollment. Elimination of the benefit design regulation perversely encourages this result. It incentivizes insurers to find roundabout ways to deter people with pre-existing conditions from their plans. This is impermissible under Section 1557 of the ACA and Section 504 of the Rehabilitation Act. See 29 U.S.C. § 794; 42 U.S.C. §§ 18116(a), 18031(c)(1)(A); 45 C.F.R. § 92.207(b)(2).

⁹ See, e.g., *HHS OCR Complaint RE: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida* (May 28, 2014), <https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/> (finding that placing all HIV/AIDS medications in the highest cost-sharing tier violates Section 1557).

¹⁰ 2016 Final Rule, 81 Fed. Reg. at 31,429.

¹¹ HHS Notice of Benefit and Payment Parameters for 2016, 80 Fed. Reg. 10,750, 10,822 (Feb. 17, 2015).

¹² CMS CCIO, *QHP Master Review Tools for 2015, Non-Discrimination in Benefit Design* (2015), available at http://insurance.ohio.gov/Company/Documents/2015_Non-Discriminatory_Benefit_Design_QHP_Standards.pdf.

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The elimination of the benefit design regulation will disproportionately harm people with disabilities, who rely on Section 1557's enforcement mechanisms to hold health insurers and health providers accountable for discriminatory practices. People with disabilities already experience significant disparities in health outcomes and access to health care.¹³ 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 disease.¹⁴ Moreover, they are nearly three times more likely to have not accessed needed health care because of cost and twice as likely to have unmet mental health needs.¹⁵ The ACA's reforms worked to reduce some of these disparities by, for example, reducing the uninsurance rate and increasing the likelihood of a person with a disability having a regular health care provider.¹⁶ However, there are still large gaps in health access,¹⁷ and persistent attitudinal and programmatic barriers to care are ongoing.¹⁸ Section 1557 provides an avenue through which people with disabilities can identify and challenge discriminatory policies—including those that manifest in the design of a health plan's benefit package. Elimination of the benefit design protections will allow health insurers to perpetuate coverage policies that exclude people with certain disabilities from benefit coverage or target the health care services, devices, and prescription drugs that people with disabilities disproportionately rely on. As a group of individuals already facing significant external barriers in the health care context, such a regression of their civil rights should not be realized.

Finally, HHS has not explained *why* it proposes to eliminate the benefit design regulation in the Proposed Rule, and it is thus impossible to provide a complete comment. The only reference to the current regulation is in Footnote 147, wherein the referenced text states that many of the current Section 1557 regulations are “duplicative of, inconsistent with, or confusing in relation to” pre-existing Section 504, Title VI, Title IX, and Age Act regulations. 84 Fed. Reg. at 27846, 27869. It is unclear which of these three factors HHS is alluding to with respect to the benefit

¹³ See, e.g., Silvia Yee, Mary Lou Breslin, et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, NAT'L ACADS. SCI., ENG'G, & MED. (2017), available at <http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities/Commissioned-Papers/Compounded-Disparities>.

¹⁴ *Id.* at 32.

¹⁵ *Id.* at 31.

¹⁶ 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, no. 7, 1015–21 (July 2019); Gloria L. Krahn, *Drilling Deeper on the Impact of the Affordable Care Act on Disability-Related Health Care Access Disparities*, 109 AM. J. PUB. HEALTH, no. 7, 956–58 (July 2019).

¹⁷ See Kaye, *supra* note 16, at 1019–21 (for example, across the population of people with disabilities, there has been “much greater delayed or forgone care” post-ACA).

¹⁸ See *id.*; Yee, et al., *supra* note 13, at 31–32; 39–44.

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design regulation. Regardless, concerns of duplication, inconsistency, or confusion in this context are unfounded. The benefit design regulation does not duplicate existing regulations. Section 1557 applies longstanding civil rights principles to the unique context of health care. Because pre-existing statutes such as Section 504 are more generally applicable and have not historically been applied to private health insurers,¹⁹ their regulations do not explain how the content of a health benefit package can discriminate. See, e.g., 28 C.F.R. Part 41 (HHS Section 504 regulations). Thus, it was necessary to explain this concept in the Section 1557 regulations. The benefit design regulation is also not inconsistent with or confusing in relation to pre-existing civil rights regulations. Its provisions do not contradict currently-existing regulations. Instead—in recognition that the ACA significantly reformed the health insurance market, increased administrative oversight of health plans, and applied nondiscrimination principles to private health insurers for the first time—the Section 1557 benefit design regulation served to explain one form of health insurer discrimination that was previously difficult to challenge.²⁰ The regulation should not be repealed on these erroneous grounds.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.207 in its entirety.

¹⁹ Prior to the ACA, private health insurance plans did not receive FFA, and thus Section 1557 and Title VI did not typically apply to them. The ACA’s creation of, e.g., premium tax credits and federal- and state-run exchanges, changed this.

²⁰ Prior to the ACA, private health insurers were generally not subject to disability nondiscrimination laws. Additionally, some lower courts misinterpreted *Alexander v. Choate*, 469 U.S. 287 (1985), to stand for the proposition that Section 504 does not reach the “content” of a health benefit, but rather only the ability to “access” the benefit. See, e.g., *Doe v. Mutual of Omaha Ins. Co.*, 179 F.3d 557 (7th Cir. 1999). These erroneous interpretations of *Choate* critically misunderstood the U.S. Supreme Court’s holding, which made clear that people with disabilities must have “meaningful access” to health care benefits. 469 U.S. at 296–99, 301. The benefit, it explained, could not be defined in a way that disparately harms people with disabilities. *Id.* For further analysis of the meaning of *Choate* in the context of ACA-regulated health plans, see Brief of DREDF, DRA, DRC, DRCL, NHeLP, and ACLU as *Amici Curiae* in Support of Neither Party, *Doe v. CVS Pharmacy, Inc.*, No. 19-15074 (9th Cir. appeal filed Jan. 1, 2019), available at <https://dredf.org/2019/07/02/doe-v-cvs-pharmacy-incl/>.

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III. DISABILITY DISCRIMINATION

A. Effective Communication (45 C.F.R. § 92.202; Proposed § 92.102)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.202 (redesignated § 92.102), regarding effective communication for individuals with disabilities. Effective communication is a critical component of accessing and receiving quality health care. DREDF often hears about entities refusing to provide effective communication or relying on communication methods that are the preference of the entity rather than the choice of the individual. Therefore, we commend HHS for holding all recipients of FFA from HHS to the higher ADA Title II standards found at 28 C.F.R. §§ 35.160–35.164. Giving primary consideration to the choice of aid or service requested by the individual with a disability helps to ensure actual effective communication and thus equal opportunity in the health care setting.

We are, however, concerned with HHS' proposed changes to the definitions relating to the effective communication regulation. First, we object generally to the deletion of the definitions at 45 C.F.R. § 92.4. The elimination of this section will cause confusion for covered entities and risk inconsistency among the various Section 1557 regulations. It also makes it more difficult to amend definitions as needed, which is especially important in the context of effective communication, as auxiliary aid technologies are constantly evolving. Second, while we appreciate HHS' efforts to incorporate many of the current ADA definitions, including the definitions of disability, auxiliary aids and services, qualified interpreter, and video remote interpreting, we note that HHS has erred in tracking the language of these longstanding definitions. The problems we have identified are as follows:

- The definition of auxiliary aids and services at proposed § 92.102(b)(1) excludes “acquisition or modification of equipment and devices” and “[o]ther similar services and actions,” despite these two items being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. HHS states in its Proposed Rule that “[t]he list of auxiliary aids and services from 28 CFR 35.104 is incorporated into the proposed rule at § 92.102(b)(1)” and in general that “[t]hese provisions are drawn from regulations implementing Title II of the Americans with Disabilities.” 84 Fed. Reg. at 27866, 27867, n. 123. This list is incomplete and HHS' statements are misleading. Parts of 28 C.F.R. § 35.104 are incorporated into the Proposed Rule, but the above-quoted language regarding the “acquisition or modification of equipment and devices” and “other similar services and actions” is missing. This deletion alters what was an open-ended functional definition; it takes what is clearly a list of examples of auxiliary aids and services in the current regulations and turns it into an exhaustive list in the proposed regulation. Moreover, to the extent that HHS claims it seeks to eliminate inconsistent applications of the law, such as change is neither prudent nor consistent with the law. We strongly oppose these deletions.

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- The definition of auxiliary aids and services at proposed § 92.102(b)(1) also excludes the term “Qualified” before “Interpreters” in subsection (i) and before “Readers” in subsection (ii), despite this critical adjective being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. While we appreciate that HHS does track the content of the ADA definition of *qualified* interpreters at proposed § 92.102(b)(2)–(3), it will enable greater clarity and consistency with the ADA regulations to keep the term “Qualified interpreters” in the auxiliary aids definition at proposed § 92.102(b)(1)(i). Moreover, the word “Qualified” has also been deleted from “readers” in proposed § 92.102(b)(1)(ii), yet the proposal fails to incorporate the ADA definition of qualified readers. The change here is not merely theoretical. Covered entities should not, for example, be free to assign the task of reading personal information about healthcare status, medical procedures, and bills to a high school student hired to help with receptionist duties over the summer. The requirement for a defined “qualified reader” helps to ensure effective communication and healthcare for people with disabilities. We strongly encourage HHS to both include the word “Qualified” in proposed § 92.102(b)(1)(ii), and incorporate the ADA definition of this term, see 28 C.F.R. § 351.04 (“Qualified reader means a person who is able to read effectively, accurately, and impartially using any necessary specialized vocabulary.”).

DREDF is also concerned with the narrowing of the “free of charge” and “timely manner” provision at proposed § 92.102(b)(2). The current Section 1557 regulations state that a covered entity must provide “appropriate auxiliary aids and services, including qualified interpreters for individuals with disabilities and information in alternate formats, free of charge and in a timely manner . . .” 45 C.F.R. § 92.8. This language echoes the ADA Title II regulations, which provide that covered entities “may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility . . .” 28 C.F.R. § 35.130(f). In proposed § 92.102(b)(2), HHS significantly narrows this provision by only stating that “*interpreting service* shall be provided to individuals free of charge and in a timely manner” (emphasis added). We strongly oppose this change and encourage HHS to replace the words “interpreting service” with “auxiliary aids and services” to be consistent with the ADA and prevent unnecessary confusion over the requirement. Covered health care entities may not legally charge for *any* auxiliary aid provided; this pre-existing legal requirement should be made clear.

Finally, HHS requests comment on whether it should add an exemption from the effective communication requirements for covered entities with fewer than 15 employees. See 84 Fed. Reg. at 27867. DREDF strongly opposes this exemption. HHS has not applied such an exemption in nearly 20 years and to apply it now would roll back the clock on the enforcement of effective communication for people with disabilities. To be clear, effective communication requirements profoundly impact threshold access to and the quality of health care that a person

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with a disability receives. Breakdowns in communication between a health care provider and a patient with a disability are reported across all types of disabilities,²¹ and the lack of accurate and effective communication can lead to misdiagnosis, erroneous treatment, and ultimately a negative impact on the health or life of the patient.²² The lack of positive health care communication experiences can also lead to a loss of trust or fear of health care providers, leading some people with disabilities to feel as if they have no choice but to rely upon self-diagnosis and treatment.²³ The provision of appropriate auxiliary aids and services can help remedy some of these health care disparities. For example, the provision of ASL interpreters to Deaf patients preferring this type of communication accommodation has been linked with significantly higher utilization rates of preventative care, including cholesterol screens, colonoscopy, and influenza vaccines.²⁴ While there are still many improvements to be made, requiring all covered entities to provide effective communication is a vital first step towards ensuring health care equity.

Provider offices with fewer than 15 employees should not be exempted from this basic civil rights requirement. People with disabilities often obtain their health care from local providers or specialists with only a few employees. This is especially true in rural areas, where providers are more likely to have smaller practices, and there may only be one appropriate specialist within a reasonable distance. Small provider practices are more common than one might think: the American Medical Association's 2012–2016 Physician Practice Benchmark Survey²⁵ found that

²¹ See, e.g., Thilo Kroll, et al., *Primary Care Satisfaction Among Adults with Physical Disabilities: The Role of Patient-Provider Communication*, 11 MANAGED CARE Q., no. 1, 11–19 (2003); Melinda Neri & Thilo Kroll, *Understanding the Consequences of Access Barriers to Health Care: Experiences of Adults with Disabilities*, 25 DISABILITY & REHAB., no. 2, 85–96 (2003); Sara Bachman, et al., *Provider Perceptions of Their Capacity to Offer Accessible Health Care For People With Disabilities*, 17 J. DISABILITY POL'Y STUD., no. 3, 130–36 (2006); Elizabeth H. Morrison, et al., *Primary Care for Adults with Physical Disabilities: Perceptions from Consumer and Provider Focus Groups*, 40 FAM MED., no. 9, 645–51 (2008).

²² See Yee, et al., *supra* note 13, at 43–44 (summarizing and analyzing the abundance of research on this point).

²³ *Id.*

²⁴ Michael M. McKee, et al., *Impact of Communication on Preventive Services Among Deaf American Sign Language Users*, 41 AM. J. PREVENTATIVE MED., no. 1, 75–79 (2011).

²⁵ Carol K. Cane, AM. MED. ASSOC., *Policy Research Perspectives: Updated Data on Physician Practice Arrangements: Physician Ownership Drops Below 50 Percent 4–5* (2017), available at <https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/health-policy/PRP-2016-physician-benchmark-survey.pdf>. The Benchmark surveys are of practicing physicians who provide a minimum of 20 hours of patient care per week in one of the 50 states or the District of Columbia and who are not employed by the federal government.

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a majority of physicians still work in small practices, with 57.8% working in practices of 10 or fewer physicians and 37.9% working in practices with fewer than 5 physicians.²⁶ Physicians in single-specialty practices were even more likely to be in small practices.²⁷ Exempting these smaller practices means that people with disabilities will have significantly more difficulty obtaining effective communication from both general and specialty physicians, and it sends the message that HHS' latest healthcare-specific civil rights regulations make it harder for people with communication disabilities to obtain needed health care. This exemption could thus function to exclude many people with disabilities from accessing the health care they need. Congress surely did not intend such a result in enacting the ACA and Section 1557.

Moreover, in practice, this exemption would make little sense because public accommodations (including hospitals and provider offices) of any size are already required to provide effective communication under Title III of the ADA. Even HHS, when it originally announced that the 15-employee exemption does not apply to entities receiving HHS funds, recognized this reality:

This is not a new requirement; Title III of the Americans with Disabilities Act (ADA) already requires public accommodations of all sizes to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication and Title II of the ADA extends the same requirement to state and local government entities. The vast majority of entities that receive federal financial assistance from HHS thus are already required to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication.²⁸

If HHS' intent is to protect small entities from costs, then the appropriate mechanisms to do so is already in 45 C.F.R. § 92.202, which incorporates the ADA Title II exemptions found in 28 C.F.R. § 35.164 by explicit reference.²⁹ Adding an exemption for small entities will harm people with disabilities and is not the proper solution.

²⁶ A practice with 10 physicians may or may not have 15 or fewer employees, but a practice with 5 physicians is very likely to have fewer than 15 employees. *Id.*

²⁷ *Id.*

²⁸ HHS OCR, Section 504 of the Rehabilitation Act of 1973; Notice of Exercise of Authority Under 45 CFR 84.52(d)(2) Regarding Recipients With Fewer Than Fifteen Employees, 65 Fed. Reg. 79368, 79368 (Dec. 19, 2000).

²⁹ 28 C.F.R. § 35.164 ("This subpart does not require a public entity to take any action that it can demonstrate would result in a fundamental alteration in the nature of a service, program, or activity or in undue financial and administrative burdens. In those circumstances where personnel of the public entity believe that the proposed action would fundamentally alter the service, program, or activity or would result in undue financial and administrative burdens, a

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RECOMMENDATIONS:

- HHS should clarify that the list of auxiliary aids and services in proposed 45 C.F.R. § 92.102(b)(1) is not exhaustive by adding the following after subsection (ii):
 - “(iii) Acquisition or modification of equipment and devices; and
 - (iv) Other similar services and actions.”
- HHS should put back the term “Qualified” before “Interpreters” in proposed 45 C.F.R. § 92.102(b)(1)(i) and before “Readers” in proposed 45 C.F.R. § 92.102(b)(1)(ii), and it should incorporate the definition of “Qualified readers” found at 28 C.F.R. § 35.104.
- The requirement to provide services “free of charge and in a timely manner” in proposed 45 C.F.R. § 92.102(b)(2) should be applied to all “auxiliary aids and services,” not just “interpreter services.”
- No exemption should be added for covered entities with fewer than 15 employees.

B. Information and Communication Technology (45 C.F.R. § 92.204; Proposed § 92.104)

DREDF supports HHS’ proposal to retain the provisions of 45 C.F.R. § 92.204 (redesignated § 92.104), regarding information and communication technology (“ICT”) for individuals with disabilities. Like effective communication, access to information, communication, and electronic technologies is important to guaranteeing people with disabilities equal access to health care services—and this fact is even more true as U.S. society increasingly relies on digital and web-based communications. Health care providers and health insurance plans are rapidly developing interactive websites, moving their medical recordkeeping online, and communicating with patients through electronic means. We commend HHS’ efforts to ensure that people with disabilities are not left behind as technologies evolve.

We are, however, concerned with HHS’ proposed change to the definition of “information and communication technology” in proposed § 92.104(c). While we generally object to the elimination of the definitions at 45 C.F.R. § 92.4, we do appreciate that HHS has incorporated the definition of ICT from the U.S. Access Board regulations implementing Section 508 of the Rehabilitation Act. We note, however, that a critical phrase was removed from the U.S. Access Board’s definition. The second sentence of the U.S. Access Board’s definition reads: “Examples of ICT include, but are not limited to: . . .” (emphasis added). 36 C.F.R. Part 1194, Appendix A, E103.4.

public entity has the burden of proving that compliance with this subpart would result in such alteration or burdens.”).

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HHS has removed the phrase “but are not limited to” in its Proposed Rule. We strongly encourage HHS to keep this phrase. Information and communication technologies are constantly evolving; it is difficult to predict what technologies will be in place in 5, let alone 10 or 20, years. In order to maintain flexibility and ensure that the regulations keep pace with emerging technologies, HHS should make it absolutely clear that its list of examples of ICT is not exhaustive.

Finally, HHS requests comment on whether it should cross-reference Section 508 and its applicable implementing regulations in proposed § 92.104. See Fed. Reg. at 27867–68. DREDF supports this proposal. Cross-referencing Section 508 and its regulations will help ensure that the Section 1557 stay up-to-date as the Section 508 regulations are amended, and it will ensure consistency across the civil rights laws.

RECOMMENDATIONS:

- HHS should amend the second sentence of proposed 45 C.F.R. § 92.104(c) to read “Examples of ICT include, but are not limited to: . . .”.
- HHS should cross-reference Section 508 and its applicable implementing regulations in proposed 45 C.F.R. § 92.104.

C. Architectural Standards (45 C.F.R. § 92.203; Proposed § 92.103)

DREDF supports HHS’ proposal to retain the provisions of 45 C.F.R. § 92.203 (redesignated § 92.103), regarding accessibility standards for buildings and facilities. We support HHS’ position that the 2010 ADA Standards for Accessible Design (“2010 Standards”) are the appropriate architectural standards for any facility or part of a facility in which health programs or activities are conducted that is constructed or altered by or on behalf of, or for the use of, a recipient or State Exchange. We appreciate HHS’ continued commitment to ensuring that health care facilities and provider offices are accessible for people with disabilities.

HHS requests comment on the appropriateness of applying the 2010 ADA Standards’ definition of “public building or facility” (i.e., the ADA Title II standards) to all entities covered under Section 1557, specifically with respect to multistory building elevators and text telephone (“TTY”) requirements. See Fed. Reg. at 27867. DREDF responds that it is indeed appropriate and *necessary* to hold all health programs and activities that receive federal financial assistance to these higher Title II standards, and we strongly oppose importing the private multistory building exception found at Section 206.2.3 of the 2010 Standards and the private entity TTY standard found at Section 217.4.3 of the 2010 Standards into Section 1557.

First, by virtue of accepting federal financial assistance from HHS, it is entirely appropriate to hold all covered health programs and activities, including private entities, to the Title II standards.

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If we look at the ADA in a vacuum, a private entity that operates as a place of public accommodation would only be subject to the lower Title III architectural standards. However, here, the ADA standards function in relation to Section 1557, which notably references and incorporates the grounds of discrimination of Section 504, not the ADA. Section 504 covers programs and activities receiving federal financial assistance. So, in this context, some private health care practices, for example, would be on the hook for not only being a public accommodation under Title III, but also an entity that avails itself to nondiscrimination law (Section 504 and Section 1557) by virtue of choosing to accept federal financial assistance from HHS. This distinction justifies holding private health care entities to a higher standard, which even HHS itself recognized in its 2015 proposed rule:

[The] entities covered under the proposed rule are health programs and activities that either receive Federal financial assistance from HHS or are conducted directly by HHS. Although OCR could apply Title II standards to States and local entities and Title III standards to private entities, we believe it is appropriate to hold all recipients of Federal financial assistance from HHS to the higher Title II standards as a condition of their receipt of that assistance.³⁰

Additionally, it is important to consider the context of the buildings and facilities at issue under Section 1557. While we affirm that architectural access is essential in all contexts, we note that it is particularly crucial for people with disabilities to have equal access to health programs and activities. People with disabilities already face significant barriers in accessing needed health care,³¹ and exempting a health insurance enrollment center or plan benefit counselor from having an elevator or a small health care practice from providing TTY, for example, will only serve to widen the disparities in health access. By choosing to operate a business that is critical to an individual's health and life, and then by choosing to accept HHS funds, private health entities have also assumed a duty to ensure that their buildings and facilities are accessible for all. These are also obligations that are inevitably included in the contracts that health entities enter into when they agree to function as a plan or provider with Medicaid, Medicare, or through an Exchange. Watering down this responsibility is unacceptable and unlawful. It will function to reward those few construction or alteration projects that did not have the foresight to take into account the needs of healthcare consumers with disabilities.

As to the two exemptions that HHS specifically requests comment on, DREDF strongly opposes them both. Section 206.2.3 of the 2010 Standards provides, in relevant part, that "[i]n private buildings or facilities that are less than three stories or that have less than 3000 square feet (279 m²) per story, an accessible route shall not be required to connect stories provided that the building or facility is not . . . the professional office of a health care provider . . . or another type

³⁰ 2015 Proposed Rule, 80 Fed. Reg. at 54186.

³¹ See, e.g., Yee, et al., *supra* note 13; Kaye, *supra* note 16.

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of facility as determined by the Attorney General.” This private elevator exemption dates back to the 1991 ADA Standards for Accessible Design, a time period in which the concept of widespread architectural accessibility was still relatively recent and wherein the construction or addition of accessible elevators was still considered extremely burdensome and costly. Today, private entities have had over 50 years³² to adjust their architectural designs and consider the needs of people with disabilities. No longer is requiring a multi-story building or facility to have an elevator the foreign concept or perceived burden it once was. Instead, it is required by the law. Rolling back the standards for having an elevator in private health buildings will only serve to erect a new, additional barrier for individuals with disabilities to access needed health programs.

DREDF also opposes lowering the private entity TTY standard. Section 217.4.3 of the 2010 Standards provides, in relevant part, that “[w]here at least one public pay telephone is provided in a *public building*, at least one public TTY shall be provided in the building” (§ 217.4.3.1) and “[w]here four or more public pay telephones are provided in a *private building*, at least one public TTY shall be provided in the building” (§ 217.4.3.2). The lower 4:1 TTY standard for private entities, which originated 15 years ago,³³ is now outdated given the current widespread availability and affordability of the technology. It takes little effort or cost for covered entities to provide 1:1 TTY, yet the benefits offered to people who are Deaf or have hearing impairments are significant. Although TTY is not as commonly used as it once was, there are certain populations that still rely on TTY, including people who are DeafBlind, people living in rural areas, and senior citizens. For these individuals, TTY critically enables communication with their health care providers, their insurance companies, and other similar entities. Accordingly, HHS should not lower the 1:1 TTY standard for private health care entities.

We also encourage HHS to explicitly incorporate standards that require covered entities to accommodate newer communication technologies that are being used by people with disabilities. Since the establishment of the TTY standards, new innovations such as real-time text (“RTT”) have emerged. We urge HHS to codify language that both retains the existing TTY ratios and also adopts similar RTT ratios,³⁴ in order to be inclusive of modern technologies. Like TTY, all health care entities should be held to more stringent public entity RTT ratios. This

³² The Architectural Barriers Act, the first federal law requiring that facilities designed, constructed, altered, or leased with certain federal funds be accessible for people with disabilities, was signed into law in 1968. See 42 U.S.C. §§ 4151–57.

³³ The 4:1 private TTY standard was first adopted in the 2004 ADA Accessibility Guidelines (“ADAAG”).

³⁴ The Federal Communications Commission has adopted rules to facilitate a transition from TTY technology to RTT technology, which HHS could look to for guidance. See 47 C.F.R. Part 67.

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addition will help ensure that the Section 1557 regulations stay up-to-date with technological developments.

RECOMMENDATIONS:

- HHS should continue to apply the 2010 ADA Standards' definition of "public building or facility" to all entities covered under Section 1557.
- HHS should not incorporate the private multistory building elevator exemption into Section 1557.
- HHS should not lower the 1:1 TTY ratio for private entities under Section 1557. It should retain the existing TTY ratios and also adopt stringent RTT ratios.

D. Medical Diagnostic Equipment Standards

DREDF further recommends that HHS reference and incorporate the U.S. Access Board's Standards for Accessible Medical Diagnostic Equipment, published at 36 C.F.R. Part 1195, into 45 C.F.R. § 92.203 (as redesignated § 92.103).

In its 2016 Final Rule, HHS considered but ultimately declined to adopt specific language regarding accessibility standards for medical diagnostic equipment into Section 1557. See 81 Fed. Reg. at 31422. It explained that "the United States Access Board is currently developing standards for accessible medical diagnostic equipment and, therefore, we are deferring proposing specific accessibility standards for medical equipment." *Id.* HHS OCR has further made clear that "[o]nce the United States Access Board standards are promulgated, OCR intends to issue regulations or policies that require covered entities to conform to those standards." 80 Fed. Reg. at 54187.

On January 9, 2017, the U.S. Access Board finalized and published its comprehensive Standards for Accessible Medical Diagnostic Equipment.³⁵ Thus, it is now appropriate and necessary to incorporate these standards into the Section 1557 regulations. Specifically, we recommend that 45 C.F.R. § 92.203 (redesignated § 92.103) incorporate a subsection as follows:

- (a) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment

³⁵ ATBCB, *Standards for Accessible Medical Diagnostic Equipment: Final Rule*, 82 Fed. Reg. 2810 (Jan. 9, 2017) (codified at 36 C.F.R. Part 1195).

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shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.

- (b) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

While we recognize that HHS must still develop scoping requirements for these standards and that this process will take time, we emphasize that this development process should begin now and, while the Section 1557 regulations are being otherwise amended, the U.S. Access Board standards should be codified. DREDF is deeply aware of the degree to which the common lack of accessible medical equipment presents grave barriers to effective healthcare for people with mobility, strength, and other disabilities.³⁶ Now that we have comprehensive, vetted standards to combat these widespread access barriers, HHS should take steps to require health care facilities to follow them.

RECOMMENDATION: At 45 C.F.R. § 92.203 (redesignated § 92.103), HHS should incorporate the follow subsection:

- (a) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.
- (b) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

E. Reasonable Modifications (45 C.F.R. § 92.205, Proposed § 92.105)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.205 (redesignated § 92.105), regarding covered entities' requirement to make reasonable modifications to policies, practices, or procedures. This language of "reasonable modification" conforms to other nondiscrimination regulations that apply to state and local governments and public

³⁶ See, e.g., Nancy M. Mudrick, Mary Lou Breslin, et al., *Physical Accessibility in Primary Health Care Settings: Results from California On—Site Reviews*, 5 DISABILITY & HEALTH J. 159–67 (2012); Tara Lagu, et al., *Access to Subspecialty Care for Patients with Mobility Disabilities: A Survey*, 158 ANN. INTERN. MED., no. 6, 441–46 (2013).

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accommodations (including hospitals and medical providers), and therefore it is consistent with other regulatory schemes that are already applicable to many covered entities. The 2016 Final Rule specifically applies the definition of “reasonable modification” from Title II of the ADA (state and local governments), which we believe continues to be the appropriate standard for recipients of federal financial assistance, programs established under Title I of the ACA, and programs administered by HHS. The concept of “reasonable modification” is not burdensome. It has long applied to a broad swath of entities, whether public or private, and it is therefore clear and familiar to most entities covered under Section 1557.³⁷ There is no reason to make any changes to this language, nor to import unrelated concepts from other regulatory schemes.

HHS has, however, requested comment on whether the following language should be substituted for the proposed 45 C.F.R. § 92.105: covered entities shall make “reasonable accommodation to known physical or mental limits of an otherwise qualified” individual with a disability. HHS also asks whether an exemption for “undue hardship” should be imported from 45 C.F.R. § 84.12 and 28 C.F.R. § 92.205 into proposed 45 C.F.R. § 92.105. The answer to both questions is no. HHS should not make any changes to the language at current 45 C.F.R. § 92.205.

As a preliminary matter, in asking about the imported language, HHS states that the language is taken from HHS Section 504 regulations and the “Department of Justice’s Section 504 coordinating regulation.” See 84 Fed. Reg. at 27868. However, both citations to the DOJ Section 504 coordinating regulations are to a non-existent portion of the Code of Federal Regulations.³⁸ These incorrect citations makes it impossible for the public to know with certainty what HHS is proposing, and it does not allow the public to analyze the context of the proposed imported

³⁷ See, e.g., 28 C.F.R. § 35.130(b)(7) (ADA Title II regulation) (“A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.”). Title III also incorporates a requirement that covered entities make “reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations.” *Id.* § 36.302(a).

³⁸ See 2019 Proposed Rule, 84 Fed. Reg. at 27868 (citing to 28 C.F.R. § 92.205 two separate times). 28 C.F.R. Part 92 contains regulations regarding the “Office of Community Oriented Policing Services (COPS),” and does not contain a § 92.205.

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language or any case law interpreting such language.³⁹ Public comment requires transparency, and the source of any imported language is an integral part of transparency.

New exemptions to the reasonable modification requirement are unnecessary and contrary to Section 1557. The concept of a “reasonable modification” is not boundless—it is already well-defined by regulation and decades of case law. In fact, the definition of “reasonable modification” is so clear that HHS declined to provide additional explanation of the term in the 2016 Final Rule.⁴⁰ The current regulations track Title II of the ADA, requiring covered entities to make a reasonable modification “unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the health program or activity.” 45 C.F.R. § 92.205. Continuing to apply the “reasonable modification” analysis to Section 1557 is logical and promotes consistency with pre-existing civil rights statutes, one of HHS’ stated goals of their NPRM. 84 Fed. Reg. at 27848. Neither Section 504 nor Title II of the ADA would permit an exemption for “undue hardship” in this context, and it is inappropriate to import such an exemption into Section 1557 where none exists in the statute itself.

Further, the suggested imported language of “reasonable accommodation,” “known physical or mental limitation,” and “undue hardship” comes directly from *employment*-related regulations, which are a distinct and specialized context. Such concepts are ill-fitting for health programs and activities, and they cannot be applied under Section 1557. For example, the definition of “undue hardship” makes little sense outside of the employment context, as it requires consideration of factors often irrelevant to health care, such as “(1) The overall size of the recipient's program or activity with respect to number of employees, number and type of facilities, and size of budget; (2) The type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) The nature and cost of the accommodation needed.” See 45 C.F.R. § 84.12. These factors make sense for employers; they do not when applied to health care. For instance, the composition and structure of a workforce and the number of employees is relevant to common employment-related accommodations, such as changes in job duties or schedules—

³⁹ It appears that HHS seeks to import DOJ’s rules for the implementation of Executive Order 12250. See 28 C.F.R. § 41.53. It is also possible that HHS intends to refer to DOJ’s rules for reasonable accommodation in employment in federally assisted programs pursuant to Section 504. See *id.* § 42.511. Either way, it is incumbent on HHS to accurately explain the source of any regulations it seeks to substitute.

⁴⁰ See 81 Fed. Reg. at 31382 (“OCR believes that defining the terms “reasonable modification” and “accessibility” in this rule is unnecessary, given the meaning that these terms have acquired in the long history of enforcement of Section 504 and the ADA in the courts and administratively. We intend to interpret both terms consistent with the way that we have interpreted these terms in our enforcement of Section 504 and the ADA and so decline to add these definitions to the final rule.”).

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but these factors are much less likely to have a bearing on common health care modifications, which may more commonly include requests for alternative evacuation plans for individuals who cannot use stairs, additional training for health care staff on how to provide services to certain individuals, ensuring lab referrals are made to accessible entities when necessary, or altering a policy to allow an individual to remain in a wheelchair and avoid unnecessary transferring while receiving treatment such as dental care. Because the factors used to analyze “undue hardship” are more appropriate for the employment context, we believe that the appropriate approach is to retain the “reasonable modification” language, which is taken from Title II of the ADA, already applies to many entities subject to Section 1557, and has a clear definition that is flexible enough to provide guidance to health care entities.

We also object to the importation of the concept of “known physical or mental limitation.” This addition will introduce confusion, suggest to covered entities that their obligations are limited, and create an undue focus on the measures that entities must take in response to requests for modifications. Disability discrimination encompasses not just inappropriate responses to requests for modifications, but also a failure of covered entities to take affirmative steps to prevent discrimination and provide needed reasonable accommodations and policy modifications. Taken in conjunction with the proposed deletion of 45 C.F.R. § 92.101, which defines discriminatory actions prohibited (discussed *supra*, Section II.A), importing the language regarding “known physical or mental limitation” could be read to limit covered entities’ obligations. Nothing in Section 1557 permits such limitations, and such an importation would be contrary to the language of Section 1557 and the larger statute within which it sits. HHS has provided no explanation of how this concept, which heretofore has been largely limited to the employment context where daily contact and exposure to an employee’s accommodation needs would be far more prevalent, would be applied in the health care context. Its application would undermine HHS’ stated purpose of the Proposed Rule, which is to promote consistency in the application of rules and to adhere to the enforcement mechanisms available in the underlying statutes. See 84 Fed. Reg. at 27849–51.

Furthermore, while we disagree with HHS’ statement that Congress only intended to permit disparate impact claims if such claims were permissible prior to Section 1557, HHS admits that many courts have permitted disparate impact claims under Section 504.⁴¹ Importing language regarding “known” limitations could be interpreted as limiting plaintiffs’ ability to bring systemic disparate impact claims or other substantive claims. If HHS intends to create such limitations, it must be explicit about its intent and do so via a transparent rulemaking process.

⁴¹ See, e.g., *McWright v. Alexander*, 982 F.2d 222, 229 (7th Cir. 1992); *Smith v. Barton*, 914 F.2d 1330, 1340 (9th Cir. 1990).

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For the foregoing reasons, we urge HHS to retain the language in proposed 45 C.F.R. § 92.105 as drafted and to not import any new exemptions or language regarding “reasonable accommodations for known physical and mental impairments.”

RECOMMENDATIONS:

- HHS should retain the current language of “reasonable modification” at 45 C.F.R. § 92.205 (redesignated § 92.105).
- HHS should not import an “undue hardship” exemption, or language of “known physical or mental limitation,” into the regulations related to reasonable modifications under Section 1557.

F. Request for Comment on Proposed 45 C.F.R. §§ 92.102–.105

HHS requests comment on whether it has struck the “appropriate balance” in proposed 45 C.F.R. §§ 92.102 through 92.105, with respect to Section 504 rights and obligations imposed on the “regulated community.” See 84 Fed. Reg. at 27868. DREDF generally agrees that, to the extent that HHS has retained protections from the 2016 Final Rule, such protections are appropriate. However, to the extent that the proposal deviates from the current regulations, as explained in detail in the previous subsections, we are extremely concerned that people with disabilities and their families will be disproportionately harmed.⁴² Additionally, we are troubled with HHS’ question and its underlying assumption. The role of an Executive agency is not to evaluate “whether the benefits of these provisions exceeds the burdens imposed by them.” See 84 Fed. Reg. at 27868. Such a balancing exercise is not called for by the ACA or the Administrative Procedures Act (“APA”), and it inserts an inappropriate level of regulatory finesse on a remedial scheme that was created by Congress and broadly intended to correct decades of harm and health care disparities.⁴³ The task of an Executive agency is to interpret and implement the enabling statute. The proposed balancing of interests may be an appropriate role for Congress, but it is not for the administrative branch. We thus disagree with the premise of this question.

HHS also generally asks whether the Section 1557 regulations are consistent with the regulatory scheme for entities that are not covered under Section 1557 (such as human services grantees), or whether underlying regulations for other civil rights statutes need to be modified. In previous

⁴² See *supra* notes 13–20 and accompanying text.

⁴³ See, e.g., 42 U.S.C. § 12101 (ADA findings and purposes). The ADA built upon Section 504, and Section 1557 follows in their footsteps. See *also* Kang v. U. Lim Am., Inc., 296 F.3d 810, 816 (9th Cir. 2002); H.R. REP. NO. 102–40, pt. 1, at 88 (1991), *reprinted in* 1991 U.S.C.C.A.N. 549, 626 (stating that “remedial statutes, such as civil rights law[s], are to be broadly construed”).

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sections, we have commented on areas where it is inappropriate to import regulations created for other contexts into Section 1557's regulatory scheme. While there are clearly other areas of nondiscrimination law where importing or exporting other regulatory regimes would be inappropriate, HHS has not provided sufficient clarity or specificity in its questions or their context in order to allow us to provide additional meaningful comment outside of our statements above.

Pursuant to the APA, if HHS proposes changes to existing regulations, then it must provide its own justification for these proposed revisions. Then, the public must be provided an opportunity to comment on HHS' explanations and perceived rationales for these changes. HHS' attempt to solicit feedback on unspecified underlying regulations that it may then use to promulgate unanticipated changes in a Final Rule violates the APA and its long-established procedures for notice and comment rulemaking. These questions would be more appropriately posed prior to the agency issuing an NPRM, such as through a Request for Information ("RFI"). We thus decline to provide additional feedback on the question of whether Section 1557 is generally aligned with underlying but unspecified regulations, but we have provided our explanations, justifications, and supporting evidence for our comments in the sections above.

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IV. SEX AND LGBTQI DISCRIMINATION

A. Sex and LGBTQI Discrimination under Section 1557 (45 C.F.R. §§ 92.4, 92.206, 92.207)

DREDF stands with our LGBTQI allies in opposing HHS' proposal to eliminate 45 C.F.R. §§ 92.4 and § 92.206, which define sex discrimination under Section 1557 to include discrimination on the basis of gender identity, sex stereotyping, pregnancy, false pregnancy, termination of pregnancy or recovery therefrom, or childbirth or related medical conditions; as well as § 92.207, which specifically prohibits discrimination against transgender individuals in health care coverage, including coverage of gender-affirming health care services.

Sex discrimination in health care has a disproportionate impact on women of color, women with disabilities, LGBTQI people, and individuals living at the intersections of multiple identities—resulting in them paying more for health care, receiving improper diagnoses at higher rates, being provided less effective treatments, and sometimes being denied care altogether. For example, a recent nationwide study of nearly 30,000 transgender individuals found that transgender people with disabilities are significantly more likely to have negative experiences with health care providers; face discrimination in the health care and social service setting; and experience cost-of-care barriers.⁴⁴ Social determinants of health, including economic instability, housing access, negative educational experiences, and poor social environment, are also markedly negative for people with transgender and disability identities.⁴⁵

As the first broad prohibition against sex discrimination and intersectional discrimination in health care, Section 1557 is crucial to ending discrimination against historically marginalized groups in the health care industry. The current regulations make clear that sex discrimination correctly includes discrimination based on gender identity, sex stereotyping, and termination of pregnancy, among other factors. See 45 C.F.R. §§ 92.4, 92.206. The Proposed Rule attempts to roll back these integral protections. Although HHS acknowledges in the preamble to the NPRM that Title IX prohibits discrimination based on pregnancy, including termination of pregnancy, it refuses to state whether HHS would enforce those protections. The scope of statutory protection

⁴⁴ S.E. James, et al., *The Report of the 2015 U.S. Transgender Survey*, NAT'L CTR. FOR TRANSGENDER EQUALITY (Dec. 2017), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>; *Health Disparities at the Intersection of Disability and Gender Identity: A Framework and Literature Review*, DISABILITY RIGHTS EDUCATION & DEFENSE FUND (July 2018), available at <https://dredf.org/wp-content/uploads/2018/07/Health-Disparities-at-the-Intersection-of-Disability-and-Gender-Identity.pdf>.

⁴⁵ NCTE, *supra* note 44; DREDF, *supra* note 44.

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under Section 1557 is clear, however, without unambiguous implementing regulations and enforcement, illegal discrimination is likely to flourish.

The elimination of the sex discrimination regulations at 45 C.F.R. §§ 92.4, 92.206, 92.207 would disproportionately harm LGBTQI people, and especially transgender, nonbinary, and gender nonconforming people, who already face unique barriers to accessing care, such as high uninsurance rates, discrimination and harassment.⁴⁶ Under the Proposed Rule, those barriers would only increase. For example, transgender, nonbinary, and gender nonconforming people assigned female at birth whose gender marker is male or nonbinary could be denied coverage for needed ongoing preventative care such as a pap smear or mammogram. Similarly, transgender nonbinary and gender nonconforming people assigned male at birth whose gender marker is female or nonbinary could be denied coverage for necessary care, such as a prostate exam. These discriminatory barriers to care will further compound when an LGBTQ individual also has a disability. For example, because of the common lack of equipment accessibility, people with disabilities are significantly less likely to be current with their pap test and mammogram.⁴⁷ It is easy to see how these barriers, when combined with weakened sex-based discrimination protections, will disproportionately harm LGBTQI people with disabilities.

The Proposed Rule would also disproportionately impact women, people of color who are pregnant, and women with disabilities, especially those living in rural areas. Women of color already face unique barriers to accessing pregnancy-related and/or abortion care, such as a discrimination, harassment, refusals of care, and high rates of pregnancy-related complications. For example, Asian American and Pacific Islander women are two times as likely to die from pregnancy-related causes than white women, Black women are three to four times more likely to die from pregnancy related complications than white women, and Native American women are more than four times more likely to die during or immediately after pregnancy than white women. Likewise, people who are pregnant and have disabilities face significant barriers to reproductive health care that are attitudinal in nature. Health care providers often regard women with disabilities as “childlike” and “asexual.”⁴⁸ Negative assumptions about their capacity or desire to have children are widespread and can result in sub-standard pregnancy and

⁴⁶ See NCTE, *supra* note 44.

⁴⁷ Yee, et al., *supra* note 13, at 31.

⁴⁸ Yee, et al., *supra* note 13, at 44 (citing Kenneth L. Robey, et al., *Implicit Infantilizing Attitudes About Disability*, 18 J. DEVELOPMENTAL & PHYSICAL DISABILITY, no. 4, 441–53 (2006); NATIONAL COUNCIL ON DISABILITY, *The Current State of Health Care for People with Disabilities* (Washington, DC: National Council on Disability) (2009); Maureen S. Milligan & Aldred H. Neufeldt, *The Myth Of Asexuality: A Survey Of Social And Empirical Evidence*, 19 SEXUALITY & DISABILITY, no. 2, 91–109 (2001); Tom Shakespeare, *Disabled Sexuality: Toward Rights and Recognition*, 18 SEXUALITY & DISABILITY, no. 3, 159–66 (2000)).

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reproductive care. The sexual health of women with intellectual disabilities is particularly neglected, leading to disparate rates of breast and cervical cancer screenings.⁴⁹ A rollback in Section 1557's sex discrimination protections will only serve to widen these health care disparities.

Further, the proposed incorporation of Title IX's exemptions is unlawful and would cause further harm to LGBTQI people, women of color, and LGBTQI and/or women with disabilities. For example, the Proposed Rule impermissibly tries to add Title IX's religious exemption to Section 1557's protection against sex discrimination, which could embolden providers to invoke personal beliefs to deny access to a broad range of health care services, including birth control, sterilization, certain fertility treatments, abortion, and gender-affirming care. Similarly, the proposal attacks abortion access by impermissibly incorporating the "Danforth Amendment," which carves out abortion care and coverage from the ban on discrimination of sex in the education context. Both attempts to incorporate exemptions from other laws violate the plain language of Section 1557 and should not be codified.

RECOMMENDATIONS:

- HHS should retain 45 C.F.R. §§ 92.4, 92.206, 92.207 in their entirety.
- HHS should not incorporate Title IX's religious and abortion exemptions.

B. LGBTQI Discrimination in Other Contexts

In addition to HHS' proposals to weaken LGBTQI rights under Section 1557 of the ACA, HHS also proposes to rollback protections against sexual orientation and gender identity discrimination across all HHS health care regulations. DREDF strongly opposes this proposal.

The 2016 Final Rule implementing Section 1557 did not touch other HHS regulations. The Proposed Rule, for the first time, now attempts to erase all references to gender identity and sexual orientation across a wide range of HHS administered and/or financially assisted programs

⁴⁹ Yee, et al., *supra* note 13, at 44 (citing Nechama Greenwood & Joanne Wilkinson, Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective, 2013 INT'L J. FAMILY MED. 1–8 (2013); Joshua A. Salomon, et al., *Common Values in Assessing Health Outcomes from Disease and Injury: Disability Weights Measurement Study for the Global Burden of Disease Study 2010*, 380 LANCET, no. 9859, 2129–43 (2012); Judith K. Barr, et al., *Understanding Barriers to Participation in Mammography by Women with Disabilities*, 22 AM. J. HEALTH PROMOTION., no. 6, 381–85 (2008); Susan M. Havercamp & Haleigh M. Scott, *National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities*, 8 DISABILITY HEALTH J., no. 2, 165–72 (2015)).

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and activities, including private insurance and education programs. If this proposal were codified, it would significantly weaken the health care rights of already-disadvantaged groups and serve to widen disparities in access to health care and health outcomes across the country.

Prior to the passage of the ACA, being transgender was treated as a “pre-existing condition.” As a result, transgender people, like people with pre-existing disabilities, could not find affordable health insurance coverage. Under the Proposed Rule, states and Marketplaces could again discriminate against LGBTQI people in their eligibility determinations and enrollment periods; agents and brokers who assist with marketplace plans could discriminate in enrollment; and health insurance issuers could discriminate in their health care benefit design, marketing practices, plan premiums, or coverage decisions.

Additionally, if this Proposed Rule were codified, Medicaid managed care entities and state Medicaid programs could be emboldened to discriminate against LGBTQI beneficiaries. LGBTQI people are more likely to live in poverty than the overall U.S. population.⁵⁰ As a result, they are also more likely than non-LGBTQI people to use Medicaid.⁵¹ Within LGBTQI communities, LGBTQ people of color (24%) are more likely than white LGBTQ people (18.8%) to receive Medicaid; transgender people (21.4%) are more likely than LGBQ cisgender people (13.4%) to receive Medicaid; and LGBTQ people with disabilities (44.4%) are more likely than LGBTQ people with no disabilities (11.8%) to receive Medicaid.⁵² The Proposed Rule would impermissibly open the door to discrimination against the many LGBTQI people enrolled in Medicaid programs across the country.

⁵⁰ See, e.g., INTERSECTING INJUSTICE: A NATIONAL CALL TO ACTION (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), available at http://socialjusticesexuality.com/intersecting_injustice/.

⁵¹ Caitlin Rooney, et al., *Protecting Basic Living Standards for LGBTQ People*, CTR. FOR AM. PROGRESS (Aug. 13, 2018), <https://www.americanprogress.org/issues/lgbt/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/>; see also NAT'L HEALTH LAW PROGRAM, et al., MEDICAID AS AN LGBTQ REPRODUCTIVE JUSTICE ISSUE: A PRIMER, WHY MEDICAID IS AN LGBTQ ISSUE 2 (2019), <https://healthlaw.org/resource/medicaid-as-an-lgbtq-reproductive-justice-issue-a-primer/> (citing Kerith J. Conron & Shoshana K. Goldberg, THE WILLIAMS INST., *LGBT Adults with Medicaid Insurance* 1 (2018), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Medicaid.pdf>).

⁵² Caitlin Rooney, Charlie Whittington & Laura E. Durso, CTR. FOR AM. PROGRESS, *Protecting Basic Living Standards for LGBTQ People* (Aug. 13, 2018), <https://www.americanprogress.org/issues/lgbt/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/>.

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While these are just a few examples of where LGBTQI discrimination would proliferate were the proposal to be codified, the effects will be felt across a wide range of HHS programs. For LGBTQI people, including LGBTQI people with disabilities, health disparities will be exacerbated. The Proposed Rule cannot stand.

RECOMMENDATION: Retain all references to sexual orientation and gender identity across all HHS regulations.

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V. LANGUAGE ACCESS

DREDF stands with our allies in opposing HHS' proposal to significantly weaken Section 1557's language access rights. Discrimination on the basis of language, just like discrimination on the basis of disability, creates unequal access to health care for the individuals and families who need accommodations from their health providers or insurers. Over twenty-five million Americans are limited English proficient ("LEP").⁵³ For LEP individuals, language assistance is critical to accessing and receiving health care and health insurance. The Proposed Rule, which would repeal Section 1557 regulations relating to meaningful language access, notice, tagline, and VRI requirements, threatens the civil rights of LEP persons.

A. Meaningful Access for LEP Individuals (45 C.F.R. § 92.201, Proposed § 92.101)

DREDF opposes the weakening of the regulatory language at 45 C.F.R. § 92.201 (redesignated § 92.101), concerning meaningful access for LEP individuals. We recommend retaining the current regulations for the following reasons.

First, proposed § 92.101 inappropriately changes the regulation's language from a requirement to provide meaningful access "to each individual with [LEP]" to a requirement to ensure meaningful access "to such program or activities by [LEP] individuals." This change shifts the focus of the regulation from an *individual's rights* to the covered entity's *programs or activities*, and it would thus weaken meaningful access and run contrary to the text of Section 1557. The proposed change would enable covered entities to establish generalized policies that may give insufficient attention to the specific, and sometimes unique and intersecting, needs of an LEP individual. For example, an LEP individual who also has a visual disability may require written materials in large font Spanish, rather than just the simple, Spanish language document. The proposed regulation could make this individual's dual needs more difficult to accommodate. In Section 1557, Congress declared that "an individual shall not" be subjected to discrimination. 42 U.S.C. § 18116. Section 1557 regulations cannot offer less protection than the statute that authorizes such regulations to be promulgated. The correct emphasis in the Section 1557 regulations must be on each individual and not on the programs.

Second, we oppose HHS' proposal to codify a four-factor test to determine an entity's compliance with Section 1557's meaningful access standards. In the 2016 Final Rule, HHS endorsed a two-factor test to determine compliance with the requirements, determining that this test was consistent with Title VI, the statute referenced in Section 1557 that prohibits national origin discrimination (which encompasses language discrimination). The protections in Section

⁵³ ASIAN & PACIFIC ISLANDER AM. HEALTH FORUM, Analysis of 2017 Am. Cmty. Survey ("ACS") Data.

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1557 and its regulations cannot be anything less than those already guaranteed by Title VI. Incorporating the four-factor test now would negate the claims made by HHS in the current NPRM that it seeks to align Section 1557 with Title VI, as they are already in alignment. Additionally, in originally adopting the two-factor test that was based upon, informed by, and consistent with Title VI, HHS OCR was providing a method of articulating how it would engage in enforcement review in the health care context—a specific application of Title VI and newly created by Section 1557. The two-factor test correctly incorporates the principles in HHS' LEP Guidance and it allows HHS OCR to better explain how the factors will be considered in their application to health programs and activities under Section 1557, while also giving substantial weight to the nature and importance of the particular communication at issue.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.201 in its entirety.

B. Video Remote Interpreting Standards (45 C.F.R. § 92.201(f), Proposed § 92.101(b)(3)(iii))

Additionally, while DREDF appreciates that HHS proposes to incorporate the ADA's definition of video remote interpreting ("VRI") services⁵⁴ for the purposes of effective communication for people with disabilities, we oppose the removal of the technical and training requirements for the use of VRI for spoken language interpretation. See 84 Fed. Reg. at 27866, 27887.

VRI can provide a necessary additional tool for accommodating LEP individuals in the health care setting. Depending on the nature of the communication with a health care provider or health insurer, VRI may be more appropriate than telephonic interpretation. For example, while the telephone may be appropriate for scheduling a medical appoint, it is not appropriate for interpreting information related to trauma, mental health, or death. Non-verbal cues are critically important in many health care contexts, such as when a provider writes and explains a new prescription, and they simply cannot be observed via telephone.

VRI is also cost-efficient. While there are higher costs in equipment and training, VRI has saved costs in relation to in-person interpreting, as there are no minimums, travel time, or cancellation risks. While we maintain that in-person interpreting is still best option for the patient, VRI can be an appropriate, cost-saving alternative in some contexts. Keeping the current standards will allow the health care provider and the patient to jointly determine which technology is appropriate in a given situation, and when an entity uses those VRI services, ensure that it is a high quality video with a reliable connection.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.201(f) in its entirety.

⁵⁴ See 28 C.F.R. §§ 35.104, 36.303(f).

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C. Taglines (45 C.F.R. § 92.8)

DREDF opposes the proposed elimination of the Section 1557 regulations requiring taglines in notices in the top fifteen languages spoken by LEP individuals in the state. DREDF strongly objects to the proposed removal of the general notice requirements at 45 C.F.R. § 92.8, as explained in further detail *infra* Section VI.C. We are also concerned, for purposes of language equity, at the accompanying elimination of the tagline requirement.

The inclusion of taglines is essential for effectuating the civil rights of LEP persons. Taglines are a cost-effective approach to ensure that covered entities provide language access while not being overly burdened. In the absence of translated documents, taglines are necessary “to ensure that individuals are aware of their protections under the law, and are grounded in OCR’s experience that failures of communication based on the absence of auxiliary aids and services and language assistance services raise particularly significant compliance concerns under Section 1557, as well as Section 504 and Title VI.” 2015 Proposed Rule, 81 Fed. Reg. at 54193.

Taglines are also well-supported by existing federal and state regulations, guidance, and practice.⁵⁵ Moreover, in proposing to change this long-standing requirement, HHS has provided an insufficient regulatory impact analysis, which fails to identify and quantify costs to protected individuals. It has provided no tangible analysis on the costs and burdens to protect individuals from the removal of the notice and tagline requirements. The costs are not only reduced awareness of language services by LEP persons, but also reduced awareness by the general public about their rights as protected by Section 1557. The current regulations should be maintained.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.8 in its entirety.

⁵⁵ See 29 C.F.R. § 42.405(d)(1) (Title VI Coordination Regulations); 45 C.F.R. § 155.205(c)(2)(iii) (Marketplace and QHP Issuer Requirements); 42 C.F.R. § 438.10(d)(3) (Medicaid Managed Care Plans); 29 C.F.R. § 38.9(g)(3) (DOL WIOA Nondiscrimination Requirements); 7 C.F.R. § 272.4(b) (USDA SNAP Bilingual Requirements); 2003 HHS LEP Guidance.

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VI. IMPLEMENTATION AND ENFORCEMENT MECHANISMS

DREDF also opposes HHS' proposal to eliminate several regulations that are integral to implementing and enforcing the Section 1557's prohibition on discrimination against people with disabilities, including the regulations relating to definitions (45 C.F.R. § 92.4); the designation of a responsible employee and adoption of grievance procedures (§ 92.7); notice requirements (§ 92.8); and private right of action and compensatory damages (§ 92.301).

A. Definitions (45 C.F.R. § 92.4)

DREDF strongly opposes the deletion of 45 C.F.R. § 92.4, an essential provision that contains definitions for the Section 1557 regulations. This deletion will serve to create confusion among covered entities and inconsistency of terms among the many regulations that currently reference or otherwise rely on the underlying definitions in § 92.4.

Moreover, as an organization dedicated to enforcing the rights of people with disabilities, we are specifically concerned with HHS deletion of disability-related definitions. HHS contends that the "proposed rule retains most of the disability-rights related definitions from the current rule either explicitly . . . ; by using the definition to describing the requirements or characteristics of the entity; or by referencing underlying regulations or statutes, such as for technical accessibility standards and definitions." 84 Fed. Reg. at 27860. However, as explained in Section III.A above, the text of the Proposed Rule demonstrates that HHS has altered crucial definitions related to effective communication, without any explanation or even acknowledgement that it is doing so. We urge HHS to retain all current definitions in § 92.4

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.4 and the full definitions articulated therein.

B. Grievance Procedures and Responsible Employee (45 C.F.R. § 92.7)

DREDF opposes the elimination of the Section 1557 regulatory requirements related to the designation of a responsible employee and adoption of grievance procedures, as currently codified at 45 C.F.R. § 92.7. These requirements are critical for holding covered entities responsible for the protections provided by Section 1557. Without a designated employee and defined grievance procedure, many individuals protected by Section 1557 may not receive the information they need to avoid discrimination, identify when their rights have been violated, or seek redress for discrimination faced. Across a range of covered entities, DREDF has seen how employees can "pass the buck" when it comes to meeting requests from patients with disabilities for reasonable accommodation and policy modifications. Similarly, complaints about the failure to received needed accommodations and policy modifications can easily be ignored unless entities have clearly designated grievance procedures and assigned responsibility for disability nondiscrimination to a particular employee.

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Other federal civil rights laws require designation of a responsible employee and creation of grievance procedures; retaining the regulatory grievance procedure for Section 1557 should not create a significant or even a new burden on covered entities. HHS could also determine that processes in place to support Section 1557 are evidence of compliance with other pre-existing requirements. This regulation should be retained.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.7 in its entirety.

C. Notice Requirements (45 C.F.R. § 92.8)

DREDF strongly supports the notice and tagline requirements currently contained at 45 C.F.R. § 92.8, which ensure that covered entities inform beneficiaries, enrollees, applicants, and members of the public of the availability of language services and auxiliary aids and services, and that the entity does not discriminate on the basis of race, color, national origin, sex, age or disability. The Proposed Rule, which seeks to eliminate this regulation in its entirety, is inconsistent with Section 1557 and should not be finalized.

Title 45 C.F.R. § 92.8 requires covered entities to provide notice of the following:

- (1) The covered entity does not discriminate on the basis covered by Section 1557;
- (2) The covered entity provides auxiliary aids and services for people with disabilities;
- (3) The covered entity provides language assistance services for individuals with LEP;
- (4) How to obtain auxiliary aids and services;
- (5) How to obtain language services;
- (6) The availability of the grievance procedure; and
- (7) How to file a discrimination complaint with HHS OCR.

Section 1557's notice regulation is integral to ensuring that health care consumers are informed of their rights and the availability of needed accommodation services and complaint mechanisms. Elimination of this regulation is unjustified and would be wholly inconsistent with the text and intent of the ACA.

First, the proposed elimination of the notice requirement compromises and diminishes the primacy of the nondiscrimination message of Section 1557. To clearly communicate a covered entity's nondiscrimination obligations and an individual's right to access services, a notice must be posted in physical locations, on websites, and sent with significant documents, as the current regulations provide. If an individual enters an emergency department, for example, he or she needs to know immediately how to obtain auxiliary aids and services; otherwise, his or her medical care, health, and even life may be compromised. Similarly, if an individual cannot communicate with their insurance provider to obtain information on how to access covered services or benefits, they may suffer serious harm and be forced to forgo necessary care.

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Eliminating the notice requirement will cause many individuals to not know of their rights or how to obtain necessary services. As HHS itself noted, “repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities.” 84 Fed. Reg. at 27883. Any burdens of wall space and use of information technology, staff, and resources to post the notice and include it on a website are greatly outweighed by the benefits of having the notice visible and conspicuous such that individuals may access the services promised by Section 1557 and as outlined in the notice.

Second, the notice requirements of Section 1557 are not duplicative of any other requirements, including those of Section 504 or Title VI. The notice requirements in the current regulations are explicit and designed to adequately inform individuals of the scope of their rights under Section 1557. Additionally, Section 1557 applies to a broader array of covered entities than the civil rights laws on which it builds. It applies specifically to federally-administered health programs and activities, as well as entities created under Title I of the ACA. By eliminating the notice requirements, HHS has effectively exempted a large swath of covered entities from informing individuals of their civil rights.

Third, while we recognize that some covered entities have raised concerns about how often they have to send the Section 1557 notice with significant documents, this burden does not justify the wholesale elimination of the requirement. Rather, HHS could consider a variety of other options, including an explanation of what constitutes significant documents or how often a covered entity has to send a notice if the covered entity sends multiple significant documents to individuals over the course of a year. Indeed, in comments submitted by health insurers and medical associations in response to the 2015 Proposed Rule, the overriding question was about the frequency of sending notices or taglines rather than the need to send them at all.

Finally, HHS fails to provide adequate evidence for its purported cost-saving justifications. HHS fails to calculate the specific costs related to posting notices, focusing almost entirely on the cost associated with mailings. Its analysis also does not separate out the costs for providing notices of nondiscrimination versus the costs related to including taglines in other languages, thereby making it impossible to appropriately understand which costs are related to providing these notices in English and which costs are related to taglines. Further, HHS fails to explain why completely eliminating the notice requirements is justified given the prior analysis it undertook in adopting these requirements just a few short years ago. By not fully explaining why the elimination of this important requirement is necessary, HHS fails to justify its proposal. We oppose the repeal of requirements related to notices.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.8 in its entirety.

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D. Enforcement Mechanisms (45 C.F.R. § 92.301, Proposed § 92.5)

DREDF further objects to HHS' proposal to eliminate 45 C.F.R. § 92.301 ("Enforcement Mechanisms") and replace it with proposed § 92.5, as the latter incorrectly interprets the standard of discrimination under Section 1557 and it erroneously fails to recognize a private right of action for compensatory damages.

In the Proposed Rule, HHS incorrectly attempts to limit the remedies available under Section 1557. Congress intentionally designed Section 1557 to build upon and expand prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. Section 1557 expressly provides individuals access to any and all of the "rights, remedies, procedures, or legal standards available" under the cited civil rights statutes, regardless of the type of discrimination. Rather than recognizing that the statute creates a single standard for addressing health care discrimination, HHS' reinterpretation of the statute in this proposal would instead attempt to create multiple, piecemeal legal standards and burdens of proof derived from different statutory contexts. This interpretation is contrary to Section 1557's statutory language and Congress' intent.

The proposed language is not a valid interpretation of Section 1557. While the statute expressly sets out the grounds of discrimination by reference to pre-existing civil rights statutes, it does not incorporate separate and distinct remedies, legal standards, and burdens of proof for each of the prohibited bases of discrimination.⁵⁶ To the contrary, Congress specified that "[t]he enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purposes of violations of this subsection." 42 U.S.C. § 18116(a) (emphasis added). The use of the disjunctive "or" indicates that *any* of the enforcement mechanisms applicable under any of the incorporated statutes are available to every claim of discrimination under Section 1557, regardless of the particular protected class triggering the claim. Applying standard rules of construction, all of the enforcement mechanisms provided for and available under each of the generally incorporated statutes in Section 1557 are available to every claim of discrimination under Section 1557.

It is also necessary to read Section 1557 as establishing a single standard for health care discrimination in order to avoid "patently absurd consequences."⁵⁷ HHS' proposal "would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section

⁵⁶ See, e.g., Sarah G. Steege, *Finding A Cure in the Courts: A Private Right of Action for Disparate Impact in Health Care*, 16 MICH. J. RACE & L. 439, 462 (2011) ("[T]here is no indication in § 1557 that each listed statute's enforcement mechanisms apply only to its own protected classes."); *Rumble*, 2015 WL 1197415, at *10–11.

⁵⁷ See *United States v. Brown*, 333 U.S. 18, 27 (1948).

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1557 plaintiff depending on whether the plaintiff's claim is based on her race, sex, age, or disability."⁵⁸ Moreover, courts would be left without guidance on how to address intersectional claims: should a person who alleges discrimination on the basis of both race and age be subject to the standards and enforcement mechanisms under a title IX analysis or the ADEA? Congress explicitly adopted one provision to prohibit all discrimination in health care. It strains imagination to read that one provision to require agencies and courts to apply a hodgepodge of different standards and enforcement mechanisms.

Further, the proposed changes do not comport with congressional intent. Congress did not intend the enforcement mechanisms and standards available under Section 1557 to be tethered to the nature of the claim. Rather, in enacting Section 1557, Congress sought to "create a new right and remedy in a new context without altering existing laws."⁵⁹ Congress has repeatedly expressed that it intends civil rights laws to be broadly interpreted in order to effectuate their remedial purposes.⁶⁰ By trying to narrowly limit the legal standards and burdens of proof that apply to those who have experienced health care discrimination, HHS' interpretation of Section 1557 would ignore Congress' intent to provide broad remedies to address discrimination.

Some courts have interpreted Section 1557 to apply different enforcement mechanisms and standards depending on the individual's protected class, citing Section 1557's reference to the enforcement mechanisms of the four cited civil rights statutes.⁶¹ However, the courts in these cases miscomprehend the statutory language, its context, and U.S. Supreme Court case precedent. The Supreme Court has already held that a statute's incorporation of another statute's enforcement mechanisms does not necessarily incorporate its standards of actionable discrimination.⁶² Moreover, as previously discussed, Section 1557 expressly provides for broad and uniform enforcement that is consistent with Congress' intent that civil rights laws provide broad remedies. While Congress could perhaps have more clearly articulated its intent to establish a single statutory standard for determining discrimination and enforcing Section 1557, its failure to perfectly articulate such a standard does not necessitate the narrow reading of the

⁵⁸ See *Rumble*, 2015 WL 1197415, at *11.

⁵⁹ *Id.* at *11, n.6.

⁶⁰ See, e.g., *Kang v. U. Lim Am., Inc.*, 296 F.3d 810, 816 (9th Cir. 2002); see also H.R. REP. NO. 102-40, pt. 1, at 88 (1991), *reprinted in* 1991 U.S.C.C.A.N. 549, 626 (stating that "remedial statutes, such as civil rights law[s], are to be broadly construed").

⁶¹ See, e.g., *SEPTA v. Gilead*, 102 F. Supp. 3d 688, 699 n.3 (E.D. Pa. 2015); *Briscoe v. Health Care Serv. Corp.*, 281 F. Supp. 3d 725, 738 (N.D. Ill. 2017); see also, e.g., *Doe v. BlueCross BlueShield of Tenn., Inc.*, 926 F.3d 235, 241 (6th Cir. 2019).

⁶² See *CONRAIL v. Darrone*, 465 U.S. 624 (1984) (holding that Section 504's incorporation of the "remedies, procedures, and rights" set forth in Title VI did not mean that Section 504 incorporated Title VI's substantive limitations on actionable discrimination).

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statute articulated in the NPRM and the cases it cites.⁶³ These cases overly rely on interpretations of the underlying statutes without recognizing the inherent shifts that the ACA made in the health care realm.⁶⁴ If Section 1557 were limited by the constraints of the referenced statutes, its passage would have been largely unnecessary, as the four civil rights statutes already apply to organizations “in the business of providing . . . health care.”⁶⁵

Finally, we also oppose HHS’ proposed elimination of § 92.301(b), concerning Section 1557’s private right of action for compensatory damages. Every court that has ruled on the question has found that the statutory language of Section 1557 confers a private right of action. The existence of such a right is clear from Section 1557’s statutory language, which explicitly references the “enforcement mechanisms” of the four civil rights laws listed—*all of which* contain a private right of action. Once again, this understanding is also consistent with Congress’ intent for civil rights laws to be broadly interpreted to effectuate their remedial purposes. Removing the regulatory language that confirms Section 1557’s private right of action and available damages will serve only to confuse. HHS should not finalize this proposal.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.301 in its entirety.

⁶³ See *King v. Burwell*, 135 S. Ct. 2480, 2492 (2015) (noting that the ACA “contains more than a few examples of inartful drafting” and thus emphasizing the importance of considering the broader context of the statute).

⁶⁴ The Supreme Court has recognized that the ACA’s broad purpose is to “expand insurance coverage . . . [and] ensure that anyone can buy insurance.” *Id.* at 2493. An expansive prohibition on health care discrimination is key to ensuring that *anyone* can buy insurance. Thus, other courts have properly concluded that a single standard and burden of proof apply to Section 1557: “looking at Section 1557 and the [ACA] as a whole, it appears that Congress intended to create a new, health-specific, anti-discrimination cause of action that is subject to a singular standard, regardless of a plaintiff’s protected class status.” *Rumble*, 2015 WL 1197415, at *10.

⁶⁵ See, e.g., 29 U.S.C. § 794 (Section 504 of the Rehabilitation Act).

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VII. CONCLUSION

People with disabilities, like all people, have intersectional identities. The anti-discrimination mandate in Section 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities, such as race and disability, age and disability, or sex and disability. We therefore strongly oppose the proposed changes to the Section 1557 regulations, which seek to eliminate and limit protections for LEP individuals, LGBTQI persons, women, *and* persons with disabilities and chronic conditions. Section 1557 addresses not only protections for each protected class covered, but the intersection of those protections. As such, this proposal's attack on the civil rights of one group is an attack on the civil rights of all. We stand in solidarity with other marginalized groups in objecting to these proposed changes.

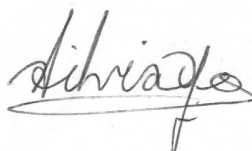
We strongly recommend that HHS not finalize any part of the Section 1557 Proposed Rule or the other conforming provisions. HHS should instead leave the current Section 1557 regulations, as codified by the 2016 Final Rule, in place in their entirety.

Thank you again for the opportunity to comment on the proposed rule. Please do not hesitate to contact us if you have any questions about the above.

Sincerely,



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Staff Attorney



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