

Submitted via regulations.gov

September 29, 2022

Ms. Melanie Fontes Rainer
Director, Office for Civil Rights
U.S. Department of Health and Human Services
Attention: 1557 NPRM (RIN 0945-AA17)
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: Nondiscrimination in Health Programs and Activities (RIN: 0945-AA17)

Dear Director Fontes Rainer,

The American Public Health Association (APHA), along with 66 public health and health policy deans, chairs, and scholars (in their individual capacity), submit these comments in strong support of your agency’s proposed rule, “Nondiscrimination in Health Programs and Activities.” With this action, HHS proposes to make critical revisions to current regulations that implement Section 1557 of the Affordable Care Act (ACA).

Section 1557 represents a landmark in the effort to end discrimination in federally assisted health activities. Despite its strengths, the American health system has a long history of discrimination based on race, color, national origin, sex, disability, and age. Over decades, U.S. civil rights laws have attempted to at least partially address this history. But these prior laws suffered from serious limits regarding the classes of individuals they protected and the range of federally assisted activities to which they applied. Section 1557 is intended to rectify these prior failings and strengthen the protective umbrella against discrimination in activities that receive federal financial assistance.

We applaud your agency’s sweeping efforts to fully implement Section 1557 by proposing new regulations that would correct the significant errors and omissions contained in the existing regulations, strengthen key provisions of the original version of the rule (published in 2016 (81 Fed. Reg. 31375)). These proposed rules would ensure that the Section 1557 regulatory framework accurately reflects both the statutory text and underlying Congressional intent.

Amici have a deep interest in ensuring strong enforcement of Section 1557 and other federal civil rights laws. The American Public Health Association (APHA) champions the health of all people and all communities, strengthens the profession of public health, shares the latest research and information, promotes best practices, and advocates for public health issues and policies grounded in scientific research. APHA represents more than 22,000 individual members and is the only organization that combines a 150-year perspective, a broad-based member community, and the ability to influence federal policy to improve the public’s health. APHA has long been known for its leadership in public health, health care, and civil rights.

The individual signatories are deans, chairs, and scholars at the nation’s leading academic institutions and research universities. They are experts in the fields of health law, public health, health care policy and research, and national health reform. They include individuals known for their expertise in health care for underserved patients and populations at risk for severe inequities in health care and health outcomes. Many are leaders in the field of health equity research and policy and have devoted much of their professional careers to research and policy development focusing on health equity for people who have long experienced health system discrimination based on sex, race, color, national origin, age or disability, or a combination of factors. The complete list of individual commenters is included at the end of this letter.

We begin our comment with general observations about the great strengths of the rule. We then turn to several comments to clarify its provisions and identify ways in which the rule can be given greater force and effect.

General comments

- We strongly support the proposal to clarify that Medicare Part B constitutes federal financial assistance for purposes of Section 1557 enforcement, as well as enforcement of Title VI, Section 504 of the Rehabilitation Act of 1973, Title IX of the 1972 Education Amendments, and the Age Discrimination Act. Without question, payment under Medicare Part B represents federal financial assistance, as is the case with other Medicare payments under Parts A, C and D. The Medicare Part B exemption was a historical anomaly meant to preserve a time when, in many states, separate “Whites Only” signs and separate entries dotted countless medical practices across the health care landscape. It is a searing commentary on civil rights and health care that such an exemption was the price paid for passage of Medicare itself,¹ and for two long, permitting this policy to remain on the books has undermined the very essence of health justice regardless of race, color, or national origin. Medicare Part B constitutes federal financing regardless of the particular health care delivery arrangement that receives federal Medicare funding.
- We strongly support the proposal to restore Section 1557’s application to all health programs or activities that receive funding under federal health programs administered by the Department. This correction reflects the scope of Section 1557, which takes an “all of health and health care” approach to U.S. civil rights laws governing federally assisted activities. It is essential that this rule restore a broad definition of what constitutes a federally assisted activity. This proposal will ensure that the rule conforms to clear statutory text. In a health system in which federal funding plays such a foundational role in both public and private insurance financing and in which coverage and care have become so intertwined, it is essential to clarify the applicability of nondiscrimination duties to the entire continuum of modern hybrid systems of coverage, care, and payment.
- We strongly support the proposal (§ 92.101) to clarify the scope and meaning of discrimination based on sex, as defined by the United States Supreme Court in *Price Waterhouse v Hopkins* and *Bostock v Clayton County*. These seminal decisions make unequivocally clear that discrimination based on sex includes sexual stereotypes, sexual orientation, and gender identity, including transgender status. The scope of this rule must reflect the whole meaning of sex-based discrimination to ensure enforcement of Section 1557

¹ David Barton Smith, *Health Care Divided* (Univ. of Michigan Press, 1999)

to the fullest extent. We also strongly support the Department's decision to clarify that discrimination based on sex includes sex characteristics, including intersex traits, because such discrimination is inherently sex-based. In response to the Department's question, we strongly recommend that the meaning of sex-based discrimination be expanded to include discrimination based on pregnancy, given the urgency of ensuring protections against efforts by certain federally-assisted entities to withhold health care essential to both the life and health of people who are pregnant.

We further suggest that the Department revise the proposed section on equal program access based on sex (§ 92.206) to reference instances of discrimination based on transgender status specifically; this revision will clarify that transgender status can constitute a separate and independent basis for enforcing the prohibition against withholding health services (including services offered exclusively to individuals of one sex) from an individual. A similar revision should also be made to § 92.207 on health insurance and other health-related coverage discrimination.

In addition, we support your agency's decision not to extend Title IX exemptions to federally funded health activities. Recognizing such exemptions in the context of health care simply would shield critical health services from the reach of civil rights protections. Of particular concern in this regard is hospital emergency care. Unlike education, people who need emergency care have little to no ability to select the source of this care; indeed, constraints on access to health care, along with limited ability to choose the source of care, affects all populations at historic risk for health inequity as a result of discrimination based on race, color, national origin, sex, or disability. To balance its decision not to provide an across-the-board exemption to religious entities, the Department appropriately would establish specific procedures for entities that seek a case-specific determination of whether they qualify for a conscience exemption (§ 92.302); this process would allow the Department to balance the request for an exemption against the specific harms of granting such an exemption.

- We support the requirement that covered entities develop and implement written compliance policies and procedures (§ 92.8) to promote a clear understanding of the rule's scope and requirements and ensure proper adoption system-wide. We understand that smaller entities may not have the resources to maintain a full-time coordinator (§ 92.7). Still, the rule should be revised to clarify that all entities have a designated coordinator regardless of size. We further recommend that the rule specify that planning should focus on the language needs of people with disabilities and those whose primary language is not English.
- We strongly support the rule's Notice requirements (§ 92.10). We recommend that the Department modify the rule to require religious entities that have received any type of exemption to notify the public regarding the specific kind of activity from which they are exempt and the basis of the exemption. We also underscore the need for model notices and information on securing translation into relevant languages or communication modalities.
- We support the Department's recognition of the intersectional nature of discrimination; indeed, Section 1557, by its terms, reflects the fact that patients can simultaneously experience

discrimination on multiple grounds – e.g., race and disability²; race and gender.³ To bring further clarity, we recommend that the Department specify that under § 92.101, people may experience discrimination based on a combination of factors.

- We strongly support the Department’s proposals to strengthen provisions related to qualified interpreters for people with limited English proficiency and those with disabilities. (§§ 92.201 and 92.202). We recommend strengthening requirements related to interpreters for people with disabilities to clarify that: interpreters display proficiency in the relevant alternative communication modality; interpretation takes place without changes, omissions, or additions; and interpreters preserve the tone, language, and emotional level of the original communication; and adherence to confidentiality principles. We also support the Department’s clarification that individuals cannot be required to provide their own interpreters, nor can minors be used to translate outside emergency situations. Additionally, we appreciate the Department’s decision to address machine translation as a specific form of activity to which the rule applies.

Specific comments related to benefit and coverage design

Provider networks.

We recommend that the Department revise its proposed benefit design rule (§ 92.207) to address provider networks as an explicit aspect of benefit design practices that potentially could form a basis for a discrimination complaint. To be sure, § 92.207(f) states that “the enumeration of specific forms of discrimination in paragraph (b) does not limit the general applicability of the prohibition in paragraph (a).” However, we are concerned with omitting any specific reference to provider networks from the rule itself. The preamble is ambiguous in our view by emphasizing that health plans have discretion over benefit design, including provider network design. This assertion, along with silence on provider networks within the rule itself, suggests that the Department has limited interest in complaints about access to care stemming from provider network composition, inclusion, competencies, and performance. These issues can profoundly affect the accessibility and quality of care for historically excluded populations.

As the Department properly acknowledges, under law narrow provider networks are a permissible and common technique some insurers and managed care plans use to hold down costs. To be sure, furthermore, even in plans with broader networks, participation and payment terms can be designed in ways to encourage certain types of care and discourage others (for example, paying lower rates for medical case management of HIV/AIDS, mental illness, autism spectrum disorders - practices that may lead providers to limit certain types of diagnoses).

Beyond narrow networks lies the practice of auto-assignment, a key feature of Medicaid managed care, which the Department fails to discuss in the rulemaking. Virtually all state Medicaid programs that administer their programs in part or in whole through comprehensive managed care plans also use auto-assignment to ensure that beneficiaries have a primary care source. However, many states, rather than randomly assigning patients to plan networks, will use auto-assignment as a means of rewarding provider quality and efficiency (auto-assigned patients tend to use significantly less health

² Mary Crossley, *Embodied Injustice: Race, Disability and Health* (Cambridge University Press, 2022)

³ See the Department’s extended discussion of elevated maternal mortality rates among Black women, 87 Fed. Reg. 47831-47833

care and may be more profitable, especially for network providers whose compensation is determined according to a global rate tied to their patient panel).⁴

While discretion may be permissible in the design of networks, provider network selection and inclusion rules, compensation arrangements, referral policies, and incentives and rewards can have an enormous impact on access to medically appropriate and timely health care. Provider network formation and management techniques, even when facially neutral, can trigger discriminatory results, including discrimination based on age, disability, race, national origin, color, sex, sexual orientation, or gender identity. Furthermore, although provider networks are an aspect of benefit design, they have become a dimension of coverage in the modern health system. Especially concerning are plan choices that result in the exclusion of certain providers by virtue of the patients they treat, as well as the imposition of artificial access barriers to providers that specialize in the treatment of certain higher-risk populations such as people living with HIV/AIDS, certain ethnic groups, and people who are transgender.

By suggesting that provider networks are an area of de-emphasis for the Department as a result of plan discretion, the proposed rule may inadvertently overlook one of the most potent means for undermining health equity for vulnerable populations protected by Section 1557. Indeed, both Congress and the Department have acted in the past to address the potential harm brought about by network exclusionary practices. Indeed, Congress demonstrated a significant concern about the effects of network exclusionary practices when it included an “essential community providers” requirement for health plans sold on the Marketplace.⁵ Furthermore, CMS has long made networks a focus of its Medicaid and Medicare Advantage rules. Even implying that network practices do not fit squarely within the purview of the benefit design concerns on which Section 1557 is focused would constitute a serious error. This is especially the case since network adequacy is not simply a dispute between plans and providers; it goes to the heart of what it means in modern insurance to have coverage – particularly for lower-income people, disproportionately members of protected groups, who do not have the means to go out-of-network for care. These people are totally at the mercy of their plan networks.

For these reasons, we recommend that § 92.207(b)(2) be amended to expressly reference provider networks as a type of benefit design feature that falls within the scope of prohibited discriminatory activities.

Discrimination in plan design based on disability.

We deeply appreciate HHS’s emphasis on protections aimed at preventing benefit design discrimination based on sex. We also urge the Department to take a comparable expansive focus on the extent to which discrimination based on disability is unreasonably and arbitrarily embedded in benefit design and that the agency move to rectify this longstanding inequity. The record should be expanded to include additional evidence of discriminatory practices against individuals with disabilities that fall within Section 1557, and the rule should be revised to capture these lived experiences of discrimination.

⁴ Ndumele, C and Wallace, J. (2020). *Improving Auto-Assignment in Medicaid Managed Care*. Available at <https://onepercentsteps.com/policy-briefs/improving-auto-assignment-in-medicare-managed-care/>.

⁵ Centers for Medicare and Medicaid Services. (2013). *Frequently Asked Questions on Essential Community Providers*, Issued May 13, 2013. Available at <https://www.cms.gov/ccio/resources/fact-sheets-and-faqs/downloads/ecp-faq-20130513.pdf>.

The intentional exclusion and segregation of people with disabilities characterized American health care for generations.⁶ This burden arguably was felt most acutely by people with severe mental illness, for whom isolation from the rest of society was the social and clinical norm. *Olmstead v L.C. by Zimring* 527 U.S. 581 (1999). Health insurance systematically excluded coverage of essential treatment, especially treatment that was community-based. To the extent that care was financed, it was tied to institutionalization, even when unnecessary.

To be sure, the past few decades have witnessed considerable progress in benefit design. Public programs, most notably Medicaid, have been modified to emphasize coverage of treatment in community settings and the higher and specialized needs of affected populations. The Mental Health Parity and Addiction Equity Act prohibits many forms of discrimination in the nature and extent of mental illness coverage offered under most forms of public and private health insurance.⁷ But discrimination against people with disabilities remains a deeply-embedded and multi-faceted feature of benefit design. Unfortunately, the proposed rule contains critical ambiguities where the issue of benefit design meets the reasonable modification rule. This is no small matter in the modern health system since artificial design constraints directly affect care due to the integration of coverage and practice networks. This may be especially true for people who also experience discrimination based on race.⁸

According to the CDC, one in four Americans has a disability. However, many people with disabilities may not identify as such, partly because of the risk of stigma that disabilities continue to raise.⁹ Like other groups of individuals who experience health discrimination, the community of people with disabilities is heterogenous, with different lived and clinical experiences. But simply because people with disabilities may have more complex health care needs due to disability does not mean they necessarily must experience worse health outcomes or more negative experiences with the health care system than people who do not live with a disability. Much of this ongoing disparate treatment results from behavior within the health system itself, both in creating coverage arrangements and providing care within these arrangements. Indeed, disability bias may mean that health professionals ascribe to their patients' disabilities certain health problems that may not arise from an underlying disability but instead from the health care system's failure to accommodate in ways that would allow patients to benefit from care regardless of their disability.¹⁰

⁶ Rosenbaum, S. (2007). The Americans with Disabilities Act in a Health Care Context, *The Future of Disability in America*. The Institute of Medicine Committee on Disability in America; Field MJ, Jette AM, editors. Washington (DC): National Academies Press. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK11434/>.

⁷ The Centers for Medicare and Medicaid. (nd). The Mental Health Parity and Addiction Equity Act (MHPAEA) Factsheet. Available at https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet.

⁸ Crossley, M. (2022). *Embodied Injustice: Race, Disability and Health*. Cambridge University Press.

⁹ Bogart, K. R., Rottenstein, A., Lund, E. M., & Bouchard, L. (2017). Who self-identifies as disabled? An examination of impairment and contextual predictors. *Rehabilitation psychology*, 62(4), 553–562. <https://doi.org/10.1037/rep0000132>

¹⁰ Crossley, M. (2022). *Embodied Injustice: Race, Disability and Health*. Cambridge University Press.

Compared to their non-disabled counterparts, people with disabilities (across all disability types¹¹) are more likely to struggle with access to care.^{12, 13, 14} Certain factors contribute to limited access: poor provider communication that affects people with disabilities regardless of age;¹⁵ limited provider training and education;¹⁶ physically inaccessible facilities;^{17, 18} a feeling of devaluation and fears that their health and well-being are given limited priority, especially during periods of health system stress, including the COVID-19 pandemic;¹⁹ failure to adequately support people with disabilities through major life transitions such as moving from pediatric to adult care;²⁰ and disproportionate financial burdens owing to the higher cost of care borne by people with disabilities, who also are more likely to face socioeconomic disadvantage generally.^{21, 22, 23, 24} Even in the wake of the ACA),

¹¹ Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults - United States, 2016. *MMWR. Morbidity and mortality weekly report*, 67(32), 882–887. <https://doi.org/10.15585/mmwr.mm6732a3>; Chavis, S. E., & Macek, M. (2022). Impact of disability diagnosis on dental care use for adults in the United States: Status matters. *Journal of the American Dental Association (1939)*, 153(8), 797–804. <https://doi.org/10.1016/j.adaj.2022.03.002>

¹² Cheak-Zamora, N. C., & Thullen, M. (2017). Disparities in Quality and Access to Care for Children with Developmental Disabilities and Multiple Health Conditions. *Maternal and child health journal*, 21(1), 36–44. <https://doi.org/10.1007/s10995-016-2091-0>; Williamson, H. J., Contreras, G. M., Rodriguez, E. S., Smith, J. M., & Perkins, E. A. (2017). Health Care Access for Adults With Intellectual and Developmental Disabilities: A Scoping Review. *OTJR : occupation, participation and health*, 37(4), 227–236. <https://doi.org/10.1177/1539449217714148>

¹³ Amin, M. R., Gentile, J. P., Edwards, B., & Davis, M. (2021). Evaluation of Health Care Disparities for Individuals with Intellectual and Developmental Disabilities in Ohio. *Community mental health journal*, 57(3), 482–489. <https://doi.org/10.1007/s10597-020-00669-6>; Prokup, J. A., Andridge, R., Havercamp, S. M., & Yang, E. A. (2017). Health Care Disparities of Ohioans With Developmental Disabilities Across the Lifespan. *Annals of family medicine*, 15(5), 471–474. <https://doi.org/10.1370/afm.2108>; Mudrick, N. R., Breslin, M. L., Liang, M., & Yee, S. (2012). Physical accessibility in primary health care settings: results from California on-site reviews. *Disability and health journal*, 5(3), 159–167. <https://doi.org/10.1016/j.dhjo.2012.02.002>

¹⁴ Slayter E. M. (2010). Disparities in access to substance abuse treatment among people with intellectual disabilities and serious mental illness. *Health & social work*, 35(1), 49–59. <https://doi.org/10.1093/hsw/35.1.49>

¹⁵ Prokup, J. A., Andridge, R., Havercamp, S. M., & Yang, E. A. (2017). Health Care Disparities of Ohioans With Developmental Disabilities Across the Lifespan. *Annals of family medicine*, 15(5), 471–474. <https://doi.org/10.1370/afm.2108>

¹⁶ Iezzoni, L. I., & Long-Bellil, L. M. (2012). Training physicians about caring for persons with disabilities: "Nothing about us without us!". *Disability and health journal*, 5(3), 136–139. <https://doi.org/10.1016/j.dhjo.2012.03.003>

¹⁷ Mudrick, N. R., Breslin, M. L., Liang, M., & Yee, S. (2012). Physical accessibility in primary health care settings: results from California on-site reviews. *Disability and health journal*, 5(3), 159–167. <https://doi.org/10.1016/j.dhjo.2012.02.002>

¹⁸ Bluth, R. (2018). Disability Discrimination Laws Don't Extend to Doctor's Visits. The Washington Post. Available at https://www.washingtonpost.com/national/health-science/for-the-disabled-a-doctors-visit-can-be-literally-an-obstacle-course--and-the-laws-cant-help/2018/10/26/1917e04c-d628-11e8-aeb7-ddcad4a0a54e_story.html.

¹⁹ The National Disability Institute. (2020). COVID-19 Disability Community Survey Results: Health and Financial Crisis. Available at: <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/04/findings-from-covid-survey.pdf>

²⁰ Jensen, K. M., & Davis, M. M. (2013). Health care in adults with Down syndrome: a longitudinal cohort study. *Journal of intellectual disability research: JIDR*, 57(10), 947–958. <https://doi.org/10.1111/j.1365-2788.2012.01589.x>

²¹ Pumkam, C., Probst, J. C., Bennett, K. J., Hardin, J., & Xirasagar, S. (2013). Health care expenditures among working-age adults with physical disabilities: variations by disability spans. *Disability and health journal*, 6(4), 287–296. <https://doi.org/10.1016/j.dhjo.2013.03.002>

²² The National Disability Institute. (2019). Financial Inequality: Disability, Race and Poverty in America. Available at: <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf>

²³ Chavis, S. E., & Macek, M. (2022). Impact of disability diagnosis on dental care use for adults in the United States: Status matters. *Journal of the American Dental Association (1939)*, 153(8), 797–804. <https://doi.org/10.1016/j.adaj.2022.03.002>

²⁴ Lee, J. C., Hasnain-Wynia, R., & Lau, D. T. (2012). Delay in seeing a doctor due to cost: disparity between older adults with and without disabilities in the United States. *Health services research*, 47(2), 698–720. <https://doi.org/10.1111/j.1475-6773.2011.01346.x>

research shows that people with disabilities are 3.1 times more likely than people without disabilities to report health care access problems.²⁵ Research comparing the use of care before and following the ACA’s enactment shows that while the law reduced access barriers (particularly among young adults, low-income families, and people living with less severe disabilities), people with disabilities, especially those with severe disabilities, continue to experience disparities in care.²⁶ Disparities remain especially pronounced for people with mental health disabilities and those who are uninsured.

The COVID-19 pandemic and its aftermath have carried special implications for people with disabilities. This population experienced heightened barriers to care during the pandemic, including barriers to vaccines, healthcare, and food.^{27, 28} In addition to their high-risk status, these barriers likely contributed to high case-fatality rates among this population.²⁹ Although telehealth has been touted as a game changer in reducing access disparities for people living with disability,³⁰ research shows that telehealth has produced new accessibility problems. Research finds that people with disabilities, including elderly people, report problems with telehealth access, including design, accessibility, language, and provider competency issues.^{31 32}

Given the number of people with disabilities, discrimination in benefit design presents as an acute problem – no less so than discrimination based on gender. It is, of course, the case that certain plan features flow from the fact that across-the-board limits and exclusions would fall especially hard on people with disabilities, *Alexander v Choate*, 469 U.S. 287 (1985). But many practices go well beyond across-the-board benefit design choices that may lie beyond the power of federal agencies to prohibit. Mental health parity is an attempt to remedy this problem of benefit designs that single out specific conditions for discriminatory coverage, but the problem goes well beyond mental health care. Just as with gender bias, insurers can build disability bias into benefit designs in ways that may masquerade as “across the board” (exactly like a gender-based exclusions do) but are, in fact, highly targeted to diminish coverage and care for certain types of disabilities.

For example, an insurer may impose a “five-year rule” that bars the replacement of covered wheelchairs until they have been used for five years or longer. This rule carries no impact on people who are not living with long-term disabilities and who may need a wheelchair temporarily (for

²⁵ Kennedy, J., Wood, E. G., & Frieden, L. (2017). Disparities in Insurance Coverage, Health Services Use, and Access Following Implementation of the Affordable Care Act: A Comparison of Disabled and Nondisabled Working-Age Adults. *Inquiry : a journal of medical care organization, provision and financing*, 54, 46958017734031. <https://doi.org/10.1177/0046958017734031>

²⁶ Kaye H. S. (2019). Disability-Related Disparities in Access to Health Care Before (2008-2010) and After (2015-2017) the Affordable Care Act. *American journal of public health*, 109(7), 1015–1021. <https://doi.org/10.2105/AJPH.2019.305056>

²⁷ Assi, L., Deal, J. A., Samuel, L., Reed, N. S., Ehrlich, J. R., & Swenor, B. K. (2022). Access to food and health care during the COVID-19 pandemic by disability status in the United States. *Disability and health journal*, 15(3), 101271. <https://doi.org/10.1016/j.dhjo.2022.101271>

²⁸ Musumeci, M. & Chidambaram, P. (2021). COVID-19 Vaccine Access for People with Disabilities. The Kaiser Family Foundation. Available at <https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/>.

²⁹ Shapiro, J. (2020). COVID-29 Infections and Deaths are Higher Among Those With Intellectual Disabilities. NPR. Available at <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

³⁰ Young, D. & Edwards, E. (2020). Telehealth and Disability Challenges and Opportunities for Care. The National Health Law Program. Available at <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

³¹ Friedman, C., & VanPuymbrouck, L. (2021). Telehealth Use By Persons with Disabilities During the COVID-19 Pandemic. *International journal of telerehabilitation*, 13(2), e6402. <https://doi.org/10.5195/ijt.2021.6402>

³² Office of the Assistant Secretary for Planning and Evaluation. (2022). National Survey Trends in Telehealth Use in 2021: Disparities in Utilization and Audio vs. Video Services. Available at <https://aspe.hhs.gov/sites/default/files/documents/4e1853c0b4885112b2994680a58af9ed/telehealth-hps-ib.pdf>

example, mobility after a leg fracture experienced during a skiing accident). Such people do not depend on a wheelchair for long-term mobility. However, this type of exclusion falls harshly on people with disabilities and has the potential to relegate people with disabilities to wheelchairs that are falling apart.³³

Similarly, an insurer can claim an “across the board” limitation that builds exclusionary language right into benefit definitions. For example, it would be an across-the-board limit for the insurer to limit covered speech therapy to 30 sessions over a plan year as long as medically necessary and confirmed by diagnosis. But a far more targeted limit – akin to excluding otherwise covered surgical benefits based on the diagnosis of gender dysphoria – is a definition of speech therapy as therapy needed to “restore” speech. Masquerading as an “across the board” rule, this type of pernicious practice lurks in definitional terms buried in plan documents, does not present as a transparent across-the-board treatment limit, and, with surgical precision, excludes all covered speech therapy for children with developmental delays who need the therapy to *attain* speech. See, *Bedrick v Travelers Ins. Co.* 93 F.3d 149 (4th Cir., 1996). This is disability discrimination impersonating a facially neutral limit – the same problem as excluding surgery for gender dysphoria.

The practice of targeting specific disabling conditions for exclusions and limits is nothing new – people living with HIV/AIDS were its victims for years and in some cases remain so. The practice came to light prominently around HIV/AIDS, *McGann v H&H Music Co.*, 946 F. 2d 401 (5th Cir., 1991), and continued well beyond that date. *Doe v Mutual Ins. Co.*, 179 F. 3d 557 (1999). Indeed, the Department has recognized this longstanding effort by insurers to target certain conditions in its noted efforts (discussed in the Preamble) to stop insurers from selectively placing HIV drugs on higher cost-sharing tiers to limit enrollment by people with the condition.

This type of targeted discrimination should not have survived the nondiscrimination prohibition of the ACA’s qualified health plan standards, as outlined in the ACA’s essential health benefit requirements (42 U.S.C. § 18022), and it should certainly not survive Section 1557. As the Department readily acknowledges concerning treatments for gender dysphoria, targeting protected classes for differential treatment is just that – and are *not* simply across-the-board benefit design choices that fall with particular severity on people with higher health needs. Furthermore, insurers have ample alternative coverage control strategies that would shield an insurer from unnecessary use without these sorts of exclusionary condition/treatment carve-outs from otherwise covered services. Remedying this problem, in our view, represents a reasonable modification of insurer practice, not a fundamental alteration that requires insurers to add entire classes of covered treatments. This, in our view, is what, in a post ACA, post 1557 world the concept of fundamental alteration in benefit design should mean. The flexibility to target and excise certain disabilities from covered treatments should be a thing of the past.

In sum, while we applaud the Department’s efforts to protect people needing services related to transgender identity, we believe that the same type of targeted discrimination affects people with disabilities. The regulations should end the practice of deliberately targeting people with disabilities for differential treatment. We, therefore, recommend amending § 92.205 to prohibit benefit design features that have the purpose or effect of targeting certain disabilities for limitation or exclusion from otherwise covered benefit and service classes. The Department should also clarify in § 92.205 that

³³ Seervai, S., Shah, A., Shah, T. (2019). The Challenges of Living with a Disability in America, and How Serious Illness Can Add to Them. The Commonwealth Fund. Available at: <https://www.commonwealthfund.org/publications/fund-reports/2019/apr/challenges-living-disability-america-and-how-serious-illness-can>

the elimination of targeted exclusions based in the type of disability or diagnosis amounts to a reasonable modification of “health programs and activities”, not a fundamental alteration.

Section 1115 Medicaid experiments

We recommend that the Department address, through further implementing guidance, how Section 1557 affects approval and oversight of § 1115 Medicaid experiments, in order to avert results that discriminate against people with disabilities. Section 1115 of the Social Security Act grants broad experimental powers to the HHS Secretary to pursue and fund experimental approaches “likely to promote” the objectives of Medicaid.³⁴ Over many decades, HHS has used this power to promote essential advances in Medicaid design and program operations.³⁵ But 1115 has also been used in recent years in ways that threaten coverage for beneficiaries generally, particularly beneficiaries with conditions considered disabling. Compelled work experiments, for example, which received multiple state approvals at their height, were allowed to proceed despite the threat they posed to people living with disabilities who face barriers to working on an uninterrupted, year-round basis.³⁶ The record in these approvals reflected no pre-approval assessment of how such demonstrations might affect the population and no specific mitigation plan (assuming the demonstration was approved to go forward) for ensuring that discriminatory impact would be monitored continuously so that the first signs of impact the experiment could be halted.

Therefore, we strongly recommend that CMS take steps to clarify how Section 1557 applies to the Section 1115 approval process and the types of practices that would be considered discriminatory in experimental design or implementation.

Discrimination based on sex: provider networks.

The urgency of expressly prohibiting discrimination based on sex (including pregnancy) in coverage design can hardly be overstated. The Census Bureau reports that approximately 9.6% of the U.S. population identifies as gay, lesbian, bisexual, or non-binary.³⁷ About one million people in the U.S. identify as transgender.³⁸ Research points to the relationship between LGBTQ status and health. Two-thirds of LGBTQ adults report that they have experienced some form of discrimination because of their sexual orientation or gender identity, such as being subject to slurs, rejection by a friend or family member, being physically threatened or attacked, discriminatory and unfair treatment in a place of business or by an employer, being made to feel unwelcome at a place of worship; 30%

³⁴ The Centers for Medicare and Medicaid Services. (nd). About Section 1115 Demonstrations. Available at:

<https://www.medicare.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html>

³⁵ Rosenbaum, S., Schmucker, S., Rothenberg, S., & Gunsalus, R. (2016). How Will Section 1115 Medicaid Expansion Demonstrations Inform Federal Policy? The Commonwealth Fund. Available at

<https://www.commonwealthfund.org/publications/issue-briefs/2016/may/how-will-section-1115-medicare-expansion-demonstrations-inform>

³⁶ Musumeci, M., Foutz, J., & Garfield R. (2018). How Might Medicaid Adults with Disabilities Be Affected by Work Requirements in Section 1115 Waiver Programs? The Kaiser Family Foundation. Available at

<https://www.kff.org/medicaid/issue-brief/how-might-medicare-adults-with-disabilities-be-affected-by-work-requirements-in-section-1115-waiver-programs/>

³⁷ Anderson, L., File, T., Marshall, J., McElrath, K., & Scherer, Z. (2021). New Household Pulse Survey Data Reveals Differences between LGBT and Non-LGBT Respondents During COVID-19 Pandemic. The Census Bureau. Available at: <https://www.census.gov/library/stories/2021/11/census-bureau-survey-explores-sexual-orientation-and-gender-identity.html>

³⁸ The Centers for Disease Control and Prevention. (nd). Issue Brief: HIV and Transgender Communities. Available at: <https://www.cdc.gov/hiv/policies/data/transgender-issue-brief.html>

reported that they had been physically threatened or attacked.³⁹ These lived experiences can contribute to mental illness and poor mental health generally. Compared to their heterosexual counterparts, sexual minority adults are between 1.5 and 2.0 times more likely to report a mood or anxiety disorder and between 1.5 and 3.0 times more likely to meet the criteria for a substance use disorder.⁴⁰ Researchers have shown that lesbian, gay, and bisexual (LGB) adults report nearly twice as many bad mental health days (7.1 versus 3.9 days) compared to heterosexual adults.⁴¹ In one NIH study, researchers observed significantly elevated rates of moderate to severe depression and anxiety, as well as suicidal thoughts among transgender and non-binary participants: 57% of transgender, nonbinary participants had moderate to severe depression, and 43% reported suicidal thoughts or self-harm in the past two weeks.⁴² These results show up at an early age: transgender youth have lower social support, higher suicide idealization, higher suicide planning, and higher suicide attempts compared to cisgender peers.^{43, 44}

³⁹ Kates, J., Ranji, U., Beamesderfer, A., Salganicoff, A., & Dawson, L. (2018). Issue Brief: Health and Access to Care and Coverage for LGBT Individuals in the US. The Kaiser Family Foundation. Available at:

<https://collections.nlm.nih.gov/master/borndig/101740255/Issue-Brief-Health-and-Access-to-Care-and-Coverage-for-LGBT-Individuals-in-the-US.pdf>

⁴⁰ Turpin, R. E., Williams, N. D., Akre, E. L., Boekeloo, B. O., & Fish, J. N. (2022). Trends in Health Care Access/Experiences: Differential Gains across Sexuality and Sex Intersections before and after Marriage Equality. *International journal of environmental research and public health*, 19(9), 5075.

<https://doi.org/10.3390/ijerph19095075>

⁴¹ Nguyen, K., Trivedi, A., & Shireman, T. (2018). Lesbian, Gay, And Bisexual Adults Report Continued Problems Affording Care Despite Coverage Gains. *Health Affairs*, 37(8), 1306-1312. <https://doi.org/10.1377/hlthaff.2018.0281>.

⁴² Tordoff, D. M., Wanta, J. W., Collin, A., Stepney, C., Inwards-Breland, D. J., & Ahrens, K. (2022). Mental Health Outcomes in Transgender and Nonbinary Youths Receiving Gender-Affirming Care. *JAMA network open*, 5(2), e220978. <https://doi.org/10.1001/jamanetworkopen.2022.0978>

⁴³ Newcomb, M. E., Hill, R., Buehler, K., Ryan, D. T., Whitton, S. W., & Mustanski, B. (2020). High Burden of Mental Health Problems, Substance Use, Violence, and Related Psychosocial Factors in Transgender, Non-Binary, and Gender Diverse Youth and Young Adults. *Archives of sexual behavior*, 49(2), 645–659. <https://doi.org/10.1007/s10508-019-01533-9>

⁴⁴ Aparicio-García, M. E., Díaz-Ramiro, E. M., Rubio-Valdehita, S., López-Núñez, M. I., & García-Nieto, I. (2018). Health and Well-Being of Cisgender, Transgender and Non-Binary Young People. *International journal of environmental research and public health*, 15(10), 2133. <https://doi.org/10.3390/ijerph15102133>

Compared to the heterosexual population, sexual minority and transgender people are disproportionately affected by chronic and acute illnesses, exhibiting higher rates of arthritis, high cholesterol, diabetes, heart disease, respiratory disease, asthma, and sexually transmitted infection.^{45, 46, 47, 48, 49} The National Health and Nutrition Examination Surveys (NHANES) have found that among women, sexual minorities are more likely to report worse overall health.⁵⁰

Despite their poorer health status, transgender individuals and sexual minorities face more significant barriers to adequate health care than the heterosexual population.^{51, 52, 53} Barriers present themselves at all stages of need, from preventive and diagnostic care (such as pap smears) and having a usual source of care to advanced medical care and necessary prescription drugs.^{54, 55, 56, 57} Of particular importance for purposes of Section 1557 – and in particular how the regulations approach the issue of provider networks, as discussed above – is the fact that fear of discrimination by providers contributes to access barriers, leading to fears about using health care or complying with visit

⁴⁵ Meads, C., Martin, A., Grierson, J., & Varney, J. (2018). Systematic review and meta-analysis of diabetes mellitus, cardiovascular and respiratory condition epidemiology in sexual minority women. *BMJ open*, 8(4), e020776. <https://doi.org/10.1136/bmjopen-2017-020776>

⁴⁶ Meads, C., Martin, A., Grierson, J., & Varney, J. (2018). Systematic review and meta-analysis of diabetes mellitus, cardiovascular and respiratory condition epidemiology in sexual minority women. *BMJ open*, 8(4), e020776. <https://doi.org/10.1136/bmjopen-2017-020776>

⁴⁷ The Centers for Disease Control and Prevention. (nd). Issue Brief: HIV and Transgender Communities. Available at: <https://www.cdc.gov/hiv/policies/data/transgender-issue-brief.html>

⁴⁸ Fish, J. N., Turpin, R. E., Williams, N. D., & Boekeloo, B. O. (2021). Sexual Identity Differences in Access to and Satisfaction With Health Care: Findings From Nationally Representative Data. *American journal of epidemiology*, 190(7), 1281–1293. <https://doi.org/10.1093/aje/kwab012>

⁴⁹ Kates, J., Ranji, U., Beamesderfer, A., Salganicoff, A., & Dawson, L. (2018). Issue Brief: Health and Access to Care and Coverage for LGBT Individuals in the US. The Kaiser Family Foundation. Available at: <https://collections.nlm.nih.gov/master/borndig/101740255/Issue-Brief-Health-and-Access-to-Care-and-Coverage-for-LGBT-Individuals-in-the-US.pdf>

⁵⁰ Cochran, S. D., Björkenstam, C., & Mays, V. M. (2016). Sexual Orientation and All-Cause Mortality Among US Adults Aged 18 to 59 Years, 2001-2011. *American journal of public health*, 106(5), 918–920. <https://doi.org/10.2105/AJPH.2016.303052>

⁵¹ Koma, W., Rae, M., Ramaswamy, A., Neuman, T., Kates, J., & Dawson, L. (2020). Demographics, Insurance Coverage, and Access to Care Among Transgender Adults. The Kaiser Family Foundation. Available at: <https://www.kff.org/health-reform/issue-brief/demographics-insurance-coverage-and-access-to-care-among-transgender-adults/>

⁵² Nguyen, K., Trivedi, A., & Shireman, T. (2018). Lesbian, Gay, And Bisexual Adults Report Continued Problems Affording Care Despite Coverage Gains. *Health Affairs*, 37(8), 1306-1312. <https://doi.org/10.1377/hlthaff.2018.0281>.

⁵³ Office of the Assistant Secretary for Planning and Evaluation. (2018). Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Recent Trends and Key Challenges. Available at: <https://aspe.hhs.gov/reports/health-insurance-coverage-lgbtq>

⁵⁴ Fish, J. N., Turpin, R. E., Williams, N. D., & Boekeloo, B. O. (2021). Sexual Identity Differences in Access to and Satisfaction With Health Care: Findings From Nationally Representative Data. *American journal of epidemiology*, 190(7), 1281–1293. <https://doi.org/10.1093/aje/kwab012>

⁵⁵ Buchmueller, T., & Carpenter, C. S. (2010). Disparities in health insurance coverage, access, and outcomes for individuals in same-sex versus different-sex relationships, 2000-2007. *American journal of public health*, 100(3), 489–495. <https://doi.org/10.2105/AJPH.2009.160804>

⁵⁶ Buchmueller, T., & Carpenter, C. S. (2010). Disparities in health insurance coverage, access, and outcomes for individuals in same-sex versus different-sex relationships, 2000-2007. *American journal of public health*, 100(3), 489–495. <https://doi.org/10.2105/AJPH.2009.160804>

⁵⁷ Office of the Assistant Secretary for Planning and Evaluation. (2018). Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Recent Trends and Key Challenges. Available at: <https://aspe.hhs.gov/reports/health-insurance-coverage-lgbtq>

schedules.^{58, 59} Research documents that transgender individuals face denial of routine healthcare as a result of their transgender status,⁶⁰ especially if they are poor and depend on Medicaid for coverage.⁶¹ The denial of needed gender-affirming care has been well-documented, of course, in both research^{62, 63, 64} and case law.

Given the evidence, full recognition of the meaning of discrimination based on sex represents a vital step forward for U.S. civil rights law, as do the special protections given medically necessary transgender surgery and gender-affirming care. Although we applaud the agency for strengthening protections for this vulnerable population, we also urge HHS to explicitly identify within the regulation itself both provider networks and the accessibility of in-network care as a specific dimension of benefit design features that may form the basis of a 1557 complaint. Furthermore, as with other forms of discrimination, HHS should clarify the obligation of insurers and plan administrators to ensure that their staff, as well as the staff of the subsidiary entities with which they do business, receive explicit training on the relationship between benefit design choices and practices and activities that can amount to discrimination based on sex, disability, age, race, color, or national origin.

Discrimination based on race, color, or national origin: provider networks.

It is safe to say that no form of discrimination in health care has been the subject of as many books, studies, reports, and historical research as discrimination based on race, color, and national origin. Indeed, discrimination by federally assisted health entities was seminal to the enactment of Title VI of the 1964 Civil Rights Act.⁶⁵ As Dr. H. Jack Geiger, a founder of the U.S. community health centers movement and one of the nation's pioneers in the use of health care as a tool for fighting racial injustice, observed in his introduction to the seminal work of Michael Byrd and Linda Clayton published in 2002, “[t]o think of racism as a disease . . . is a useful metaphor but . . . inadequate to

⁵⁸ Office of the Assistant Secretary for Planning and Evaluation. (2018). Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Recent Trends and Key Challenges. Available at: <https://aspe.hhs.gov/reports/health-insurance-coverage-lgbtq>

⁵⁹ The Centers for Disease Control and Prevention. (nd). Issue Brief: HIV and Transgender Communities. Available at: <https://www.cdc.gov/hiv/policies/data/transgender-issue-brief.html>

⁶⁰ Bakko, M., & Kattari, S. K. (2020). Transgender-Related Insurance Denials as Barriers to Transgender Healthcare: Differences in Experience by Insurance Type. *Journal of general internal medicine*, 35(6), 1693–1700. <https://doi.org/10.1007/s11606-020-05724-2>

⁶¹ Bakko, M., & Kattari, S. K. (2020). Transgender-Related Insurance Denials as Barriers to Transgender Healthcare: Differences in Experience by Insurance Type. *Journal of general internal medicine*, 35(6), 1693–1700. <https://doi.org/10.1007/s11606-020-05724-2>

⁶² Tordoff, D. M., Wanta, J. W., Collin, A., Stepney, C., Inwards-Breland, D. J., & Ahrens, K. (2022). Mental Health Outcomes in Transgender and Nonbinary Youths Receiving Gender-Affirming Care. *JAMA network open*, 5(2), e220978. <https://doi.org/10.1001/jamanetworkopen.2022.0978>

⁶³ Bakko, M., & Kattari, S. K. (2020). Transgender-Related Insurance Denials as Barriers to Transgender Healthcare: Differences in Experience by Insurance Type. *Journal of general internal medicine*, 35(6), 1693–1700. <https://doi.org/10.1007/s11606-020-05724-2>

⁶⁴ Healthcare.gov. (nd). Transgender Health Care. Available at: <https://www.healthcare.gov/transgender-health-care/>

⁶⁵ See, e.g., David Barton Smith, *Health Care Divided: Race and Healing a Nation* (Univ. of Mich. Press, 1999); David Barton Smith, *The Power to Heal: Civil Rights, Medicare, and the Struggle to Transform America's Healthcare System* (Vanderbilt Univ. Press, 2016); Paul Starr, *The Social Transformation of American Medicine* (Basic Books, 1983); Institute of Medicine, *Unequal Treatment* (National Academy Press, 2003); Michael Byrd and Linda Clayton, *An American Health Dilemma: A Medical History of African Americans and the Problem of Race, Beginnings to 1900* (Routledge, 2000); Michael Byrd and Linda Clayton, *An American Health Dilemma: Race, Medicine, and Health Care in the United States 1900-2000* (Routledge, 2002).

define the reality of a moral outrage that is still, sadly, built into the very fabric of American society.”⁶⁶

How to address facially neutral practices that nonetheless exert a discriminatory impact represents one of the great health policy challenges that confront HHS under Section 1557. While *Alexander v Sandoval*, 532 U.S. 275 (2001) may have ended access to the courts by individuals who experience disparate impact discrimination under Title VI, we strongly recommend that the Department clarify that Section 1557 itself restores such a right for individuals who have been harmed by benefit designs with a discriminatory impact in violation of Section 1557.

The issue of race and health care necessarily continues to define the work of health policy researchers. In this regard, it is safe to say that certain research stands out for its importance in determining HHS’s approach to Section 1557 implementation. One such research undertaking, the subject of much of the work of the Institute of Medicine in *Unequal Treatment*, was a study conducted by Dr. Kevin Schulman and colleagues and published in 1999, which explored the role in treatment decision-making played by physician attitudes toward patients of differing race and sex backgrounds.⁶⁷ In the most graphic way, the study documented measurable differences in how physicians may likely approach the treatment of Black and female patients reporting chest pain. This research demonstrated with uncommon power the importance of health professionals’ basic perceptions about their patients. Its finding that minority patients receive less effective care has been replicated in studies almost too numerous to cite.⁶⁸

In our view, the Schulman study, as well as the extensive collection of research into differences in care we cite, underscore the value of amending the proposed rule to include the actual terms of the enforcement rule itself and not just in passing in the Preamble, the critical importance of provider networks as an element of benefit design, including issues of network selection, the size and scope of networks, referral barriers, plan oversight of networks, and the performance incentives plans use to reward their networks. These issues go to the heart of health care access and quality itself and get closest to the actual lived experience of patients.

We believe that these studies also elevate the importance of an enforcement approach that prioritizes investigations involving cases that lie at the intersection of protected classes, such as those who are female and minority (as shown in the maternal mortality data cited by HHS)⁶⁹ or people living with

⁶⁶ Byrd, M. & Clayton, L. (2002). *An American Health Dilemma: Race, Medicine, and Health Care in the United States 1900-2000*. Routledge Publishing. p. xv.

⁶⁷ Schulman, K. A., Berlin, J. A., Harless, W., Kerner, J. F., Sistrunk, S., Gersh, B. J., Dubé, R., Taleghani, C. K., Burke, J. E., Williams, S., Eisenberg, J. M., & Escarce, J. J. (1999). The effect of race and sex on physicians' recommendations for cardiac catheterization. *The New England journal of medicine*, 340(8), 618–626. <https://doi.org/10.1056/NEJM199902253400806>

⁶⁸ Schpero, W., Morden, N.; Sequist, T., Rosenthal, M., Gottlieb, D; & Colla, C. (2017). For Selected Services, Blacks and Hispanics More Likely to Receive Low-Value Care Than Whites. *Health Affairs*, 36(6), 1065-1069.

<https://doi.org/10.1377/hlthaff.2016.1416>; van Ryn, M., Burgess, D., Malat, J., & Griffin, J. (2006). Physicians' perceptions of patients' social and behavioral characteristics and race disparities in treatment recommendations for men with coronary artery disease. *American journal of public health*, 96(2), 351–357.

<https://doi.org/10.2105/AJPH.2004.041806>; Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proceedings of the National Academy of Sciences of the United States of America*, 113(16), 4296–4301.

<https://doi.org/10.1073/pnas.1516047113>; Ghoshal, M., Shapiro, H., Todd, K., & Schatman, M. E. (2020). Chronic Noncancer Pain Management and Systemic Racism: Time to Move Toward Equal Care Standards. *Journal of pain research*, 13, 2825–2836. <https://doi.org/10.2147/JPR.S287314>.

⁶⁹ 87 Fed. Reg. 47831-47833.

disabilities who are also members of racial or ethnic minority groups, or people of color who also are members of sexual minority groups.⁷⁰ A large body of research evidences the particularly heavy disparities confronted by populations whose lives place them at the juncture of these protected characteristics.

We also strongly recommend that as part of a broader strategy of which implementation of Section 1557 is just one component, HHS also amend the HCFA 1500 to require the collection of race and ethnicity data as a basic element of any provider claim across all forms of health insurance. We further recommend that insurers and managed care plans be required to collect race and ethnicity data as part of member information at the time of enrollment. It is simply not possible to understand the scope and extent of discrimination based on race, ethnicity, or national origin without a basic assurance that enrollment and claims data include this information. Without this requirement, the foundational knowledge about health system performance simply does not exist. This issue has been debated for decades, and there are many well-discussed possible strategies and approaches for ensuring accurate collection practices.⁷¹

Finally, we would note the enormous body of research produced by the COVID-19 pandemic documenting the barriers experienced by minority people – and indeed – by entire immigrant and minority communities. Whether the need was for advanced care for the sickest patients or preventive and primary health services, invariably, it was these populations that bore the greatest burdens during

⁷⁰ Gulley, S. P., Rasch, E. K., & Chan, L. (2014). Difference, disparity, and disability: a comparison of health, insurance coverage, and health service use on the basis of race/ethnicity among US adults with disabilities, 2006-2008. *Medical care*, 52(10 Suppl 3), S9–S16. <https://doi.org/10.1097/MLR.000000000000129>; Ozturk, O. D., McDermott, S., Mann, J. R., Hardin, J. W., Royer, J. A., & Ouyang, L. (2014). Disparities in health care utilization by race among teenagers and young adults with muscular dystrophy. *Medical care*, 52(10 Suppl 3), S32–S39. <https://doi.org/10.1097/MLR.000000000000194>; Horner-Johnson, W., Dobbertin, K., & Beilstein-Wedel, E. (2015). Disparities in dental care associated with disability and race and ethnicity. *Journal of the American Dental Association* (1939), 146(6), 366–374. <https://doi.org/10.1016/j.adaj.2015.01.024>; Akobirshoev, I., Mitra, M., Li, F. S., Dembo, R., Dooley, D., Mehta, A., & Batra, N. (2020). The Compounding Effect of Race/Ethnicity and Disability Status on Children's Health and Health Care by Geography in the United States. *Medical care*, 58(12), 1059–1068. <https://doi.org/10.1097/MLR.0000000000001428>; Seelman, K. L., Young, S. R., Tesene, M., Alvarez-Hernandez, L. R., & Kattari, L. (2017). A Comparison of Health Disparities among Transgender Adults in Colorado (USA) by Race and Income. *The international journal of transgenderism*, 18(2), 199–214. <https://doi.org/10.1080/15532739.2016.1252300>; Howard, S. D., Lee, K. L., Nathan, A. G., Wenger, H. C., Chin, M. H., & Cook, S. C. (2019). Healthcare Experiences of Transgender People of Color. *Journal of general internal medicine*, 34(10), 2068–2074. <https://doi.org/10.1007/s11606-019-05179-0>; The Centers for Disease Control and Prevention. (2008). Racial/Ethnic Disparities in Self-Rated Health Status Among Adults With and Without Disabilities -- United States, 2004 – 2006. Available at <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5739a1.htm>; The National Disability Institute. (2019). Financial Inequality: Disability, Race and Poverty in America. Available at: <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf>; US Department of Health and Human Services, Office of Minority Health. (2011). Ensuring Health Equity for Minority Persons with Disabilities. Available at <https://minorityhealth.hhs.gov/Assets/pdf/Checked/1/ACMHHealthDisparitiesReport.pdf>; Mahowald, L. (2021). LGBTQ People of Color Encounter Heightened Discrimination. Centers for American Progress. Available at <https://www.americanprogress.org/article/lgbtq-people-color-encounter-heightened-discrimination/>.

⁷¹ Sara Rosenbaum, “Eliminating Inequality in Health Care Demands Measurement in Real Time,” *Milbank Quarterly* (2021), available at <https://www.milbank.org/quarterly/opinions/eliminating-inequity-in-health-care-demands-measurement-in-real-time/>

the height of the pandemic⁷² and now do so once again⁷³ in the long aftermath of the immediate crisis begins to recede but the long-term consequences emerge. To be sure, many factors may contribute to this overwhelming evidence of inequity. But the health care system's responsiveness, or the lack thereof, has played a prominent role. Some of these differences may be explained by a lack of health insurance, a problem more likely to be experienced by low-income populations and disproportionately members of minority groups.⁷⁴ Most striking, however, are studies from communities in which relatively high percentages of minority residents have a form of health insurance, but for whom the accessibility and quality of care fell grievously short and who experienced far higher rates of death and long-term disability as a result. Section 1557 was intended to address the health care system's performance, and in the final rule, HHS should focus on how its provisions can be strengthened to move enforcement closer to the heart of the problem.

⁷² Rubin-Miller, L.; Alban, C; Artiga, S.; & Sullivan, S. (2020). COVID-19 Racial Disparities in Testing, Infection, Hospitalization, and Death: Analysis of Epic Patient Data. The Kaiser Family Foundation. Available at <https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-racial-disparities-testing-infection-hospitalization-death-analysis-epic-patient-data/>; Musumeci, M. & Chidambaram, P. (2021). COVID-19 Vaccine Access for People with Disabilities. The Kaiser Family Foundation. Available at <https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/>;

Shapiro, J. (2020). COVID-29 Infections and Deaths are Higher Among Those With Intellectual Disabilities. NPR. Available at <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>; Dawson, L; Kirzinger, A., Kates, J.. The Impact of COVID-19 on LGBT People. The Kaiser Family Foundation. Available at <https://www.kff.org/coronavirus-covid-19/poll-finding/the-impact-of-the-covid-19-pandemic-on-lgbt-people/>; Burgess, C. M., Batchelder, A. W., Sloan, C. A., Jeong, M., & Streed, C. G., Jr (2021). Impact of the COVID-19 pandemic on transgender and gender diverse health care. *The lancet. Diabetes & endocrinology*, 9(11), 729–731. [https://doi.org/10.1016/S2213-8587\(21\)00266-7](https://doi.org/10.1016/S2213-8587(21)00266-7)

⁷³ Yomogida K, Zhu S, Rubino F, Figueroa W, Balanji N, Holman E. Post-Acute Sequelae of SARS-CoV-2 Infection Among Adults Aged ≥18 Years — Long Beach, California, April 1–December 10, 2020. *MMWR Morb Mortal Wkly Rep* 2021;70:1274–1277. DOI: <http://dx.doi.org/10.15585/mmwr.mm7037a2>; Su, Y., Yuan, D., Chen, D. G., Ng, R. H., Wang, K., Choi, J., ... & Heath, J. R. (2022). Multiple early factors anticipate post-acute COVID-19 sequelae. *Cell*, 185(5), 881–895. <https://doi.org/10.1016/j.cell.2022.01.014>; Garjani, A., Middleton, R. M., Nicholas, R., & Evangelou, N. (2021). Pre-existing anxiety, depression, and neurological disability are associated with long COVID: A prospective and longitudinal cohort study of the United Kingdom Multiple Sclerosis Register. *medRxiv*. <https://doi.org/10.1101/2021.06.25.21259256>; Smith, D. B., Feng, Z., Fennell, M. L., Zinn, J., & Mor, V. (2008). Racial disparities in access to long-term care: The illusive pursuit of equity. *Journal of Health Politics, Policy and Law*, 33(5), 861–881. <https://doi.org/10.1215/03616878-2008-022>; Lee, K., Mauldin, R. L., Tang, W., Connolly, J., Harwerth, J., & Magruder, K. (2021). Examining racial and ethnic disparities among older adults in long-term care facilities. *The Gerontologist*, 61(6), 858–869. <https://doi.org/10.1093/geront/gnab035>

⁷⁴ Census Bureau. (2020). Health Insurance Coverage in the US: 2019. Available at <https://www.census.gov/content/dam/Census/library/publications/2020/demo/p60-271.pdf>; Office of the Assistant Secretary for Planning and Evaluation. (2021). Health Insurance Coverage Among Working-Age Adults with Disabilities: 2010–2018. Available at <https://aspe.hhs.gov/sites/default/files/2021-07/DisabilityCoverageIB.pdf>;

Koma, W., Rae, M., Ramaswamy, A., Neuman, T., Kates, J., & Dawson, L. (2020). Demographics, Insurance Coverage, and Access to Care Among Transgender Adults. The Kaiser Family Foundation. Available at: <https://www.kff.org/health-reform/issue-brief/demographics-insurance-coverage-and-access-to-care-among-transgender-adults/>; Buchmueller, T., & Carpenter, C. S. (2010). Disparities in health insurance coverage, access, and outcomes for individuals in same-sex versus different-sex relationships, 2000–2007. *American journal of public health*, 100(3), 489–495. <https://doi.org/10.2105/AJPH.2009.160804>

APPENDIX: DEANS, CHAIRS, AND PUBLIC HEALTH AND HEALTH POLICY SCHOLARS SIGNING IN THEIR INDIVIDUAL CAPACITY

Deans

1. Burroughs, Thomas E., PhD, MS, MA, Dean and Professor, SLU College for Public Health and Social Justice, Saint Louis University
2. Chandler, G. Thomas, MS, PhD, Dean and Professor of Environmental Health Sciences, Arnold School of Public Health, University of South Carolina
3. Drenkard, Karen, PhD, RN, NEA-BC, FAAN, Associate Dean of Clinical Practice and Community Engagement, School of Nursing Center for Health Policy and Medical Engagement, The George Washington University
4. El-Mohandes, Ayman, MBBCh, MD, MPH, Dean, CUNY Graduate School of Public Health & Health Policy
5. Fried, Linda P., MD, MPH, Dean and DeLamar Professor of Public Health, Mailman School of Public Health, Professor of Epidemiology and Medicine, Columbia University
6. Galea, Sandro, MD, DrPH, Dean, Robert A Knox Professor, Boston University
7. Glied, Sherry, PhD, MA, Dean, Robert F. Wagner Graduate School of Public Service, New York University
8. Godwin, Hilary, PhD, Dean, University of Washington School of Public Health
9. Goldman, Lynn R., MD, MPH, MS, Michael and Lori Milken Dean of Public Health, Milken Institute School of Public Health, The George Washington University
10. Gusmano, Michael K., PhD, Professor and Associate Dean of Academic programs, College of Health, Director, Center for Ethics, Lehigh University
11. Hoffman, Allison K., JD, Deputy Dean and Professor of Law, University of Pennsylvania Carey Law School
12. Jeffries, Pamela R., PhD, RN, FAAN, ANEF, FSSH, Dean, Vanderbilt School of Nursing, Valere Potter Distinguished Professor of Nursing, RWJF Nurse Executive Fellow Alumna, Vanderbilt School of Nursing
13. Lu, Michael C., MD, MS, MPH, Dean, UC Berkeley School of Public Health
14. Lushniak, Boris, MD, MPH, Professor and Dean, University of Maryland School of Public Health
15. Parker, Edith A., MPH, DrPH, Dean, Professor, Community and Behavioral Health, Director, Prevention Research Center for Rural Health, Professor, Public Policy Center, Office of the Vice President for Research, The University of Iowa College of Public Health
16. Pettigrew, Melinda M., PhD, Interim Dean, Anna M. R. Lauder Professor of Epidemiology, Yale School of Public Health
17. Schuster, Mark A., MD, PhD, Founding Dean and CEO, Kaiser Permanente Bernard J. Tyson School of Medicine

Chairs

18. Beckerman, Julia Zoe, JD, MPH, Teaching Associate Professor & Vice Chair, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
19. Markus, Anne R., PhD, MHS, JD, Professor and Chair, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University

20. McDonnell, Karen A., PhD, Associate Professor and Vice Chair, Department of Prevention and Community Health, Milken Institute School of Public Health, The George Washington University
21. Oberlander, Jonathan, PhD, Professor and Chair, Department of Social Medicine, Professor, Department of Health Policy & Management, University of North Carolina at Chapel Hill
22. Slifkin, Becky, PhD, Professor and Associate Chair, Department of Health Policy and Management, UNC Gillings School of Global Health
23. Thorpe, Jane, JD, Professor and Sr. Associate Dean for Academic, Student & Faculty Affairs, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
24. Wasserman, Alan G., MD, MACP, Eugene Meyer Professor, Chairman, Department of Medicine, The George Washington School of Medicine and Health Sciences

Scholars

25. Alker, Joan, M.Phil, Research Professor, McCourt School of Public Policy, Georgetown University
26. Blewett, Lynn A., PhD, MA, Professor of Health Policy, University of Minnesota School of Public Health
27. Borden, William B., MD, FACC, FAHA, Chief Quality and Population Officer, Associate Professor of Medicine and Health Policy, George Washington University Medical Faculty Associates
28. Brindis, Claire D., DrPH, Professor, Departments of Pediatrics and Obstetrics, Gynecology and Reproductive Sciences, Director, Philip R. Lee Institute for Health Policy Studies, Director emeritus and Senior Scholar, Center for Global Reproductive Health, Co-Director, Adolescent and Young Adult Health National Resource Center, Adjunct Professor, UC Hastings School of Law, University of California, San Francisco
29. Byrnes, Maureen, MPA, Teaching Instructor, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
30. Catalanotti, Jillian, MD, MPH, FACP, Associate Professor of Medicine, Associate Professor of Health Policy and Management, Director, Internal Medicine Residency Programs, The George Washington University
31. Cohen, Alan B., Sc.D., Research Professor, Markets, Public Policy and Law, Boston University Questrom School of Business
32. Frankford, David M., JD, Professor of Law, Rutgers University School of Law
33. Goldstein, Melissa M., JD, Associate Professor, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
34. Grogan, Colleen M., PhD, Deborah R. and Edgar D. Jannotta Professor, Crown Family School of Social Work, Policy, and Practice, The University of Chicago
35. Halfon, Neal, MD, MPH, Professor of Pediatrics, Public Health and Public Policy, Director, UCLA Center for Healthier Children, Families & Communities, UCLA
36. Heinrich, Janet, DrPH, RN, FAAN, Research Professor, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
37. Horton, Katherine, RN, MPH, JD, Research Professor in the Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
38. Huberfeld, Nicole, JD, Professor of Health Law, Ethics & Human Rights, Boston University School of Public Health and Professor of Law, Boston University School of Law

39. Ku, Leighton, PhD, MPH, Professor, Department of Health Policy and Management, Director, Center for Health Policy Research, Milken Institute School of Public Health, The George Washington University
40. Lantz, Paula, PhD, James B. Hudak Professor of Health Policy, Professor of Public Policy, Gerald R. Ford School of Public Policy, Professor of Health Management and Policy, School of Public Health, University of Michigan
41. Law, Sylvia A., JD, Elizabeth K. Dollard Professor of Law, Medicine and Psychiatry, Emerita Co-Director, Arthur Garfield Hays Civil Liberties Program, NYU Law School
42. Levi, Jeffrey, PhD, Professor of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
43. Mariner, Wendy K., JD, LL.M., MPH, Professor Emerita, Health Law, Ethics and Human Rights, Boston University School of Public Health
44. Mason, Diana J., RN, PhD, FAAN, Senior Policy Service Professor, Center for Health Policy and Media Engagement, School of Nursing, The George Washington University
45. Michaels, David, PhD, MPH, Professor, Department of Environmental and Occupational Health, Milken Institute School of Public Health, The George Washington University
46. Morris, Rebecca, MPP, Senior Research Associate, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
47. Murphy, Caitlin, MPA-PNP, Research Scientist, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
48. Musumeci, MaryBeth, JD, Associate Teaching Professor, Milken Institute School of Public Health, The George Washington University
49. Perreira, Krista M., PhD, Department of Social Medicine, UNC School of Medicine
50. Peterson, Mark A., PhD, Professor of Public Policy, Political Science, and Law, Department of Public Policy, UCLA Meyer and Renee Luskin School of Public Affairs
51. Pollack, Harold, PhD, Helen Ross Professor, Crown Family School of Social Work, Policy, and Practice, The University of Chicago
52. Rimer, Barbara K., DrPH, MPH, Dean Emerita and Alumni Distinguished Professor, UNC Gillings School of Global Public Health
53. Rosenblatt, Rand E., JD, Professor Emeritus, Rutgers University School of Law
54. Rosenbaum, Sara, JD, Harold and Jane Hirsh Professor of Health Law and Policy, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
55. Schneider, Andy, JD, Research Professor of the Practice, McCourt School of Public Policy, Georgetown University
56. Seiler, Naomi, JD, Associate Research Professor, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
57. Shin, Peter, PhD, MPH, Associate Professor and Geiger Gibson-RCHN Research Director, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University
58. Silberman, Pam, JD, DrPH, Professor, Director, Executive Doctoral Program in Health Leadership, Department of Health Policy and Management, UNC Gillings School of Global Public Health
59. Siminoff, Laura A., PhD, Laura H. Carnell Professor of Public Health, Department of Social and Behavioral Sciences, Temple University
60. Skinner, Daniel, PhD, Associate Professor of Health Policy, Ohio University

61. Stoltzfus Jost, Timothy, JD, Emeritus Professor, Washington and Lee University School of Law
62. Swartz, Katherine, PhD, Professor of Health Economics and Policy, Harvard T.H. Chan School of Public Health
63. Teitelbaum, Joel, JD, LL.M., Professor of Health Policy and Law, Director, Hirsh Health Law and Policy Program, Co-Director, National Center for Medical-Legal Partnership, The George Washington University
64. Vermund, Sten H., MD, PhD, Anna M.R. Lauder Professor of Public Health, Yale School of Public Health; and Professor of Pediatrics, Yale School of Medicine
65. Vyas, Amita N., PhD, MHS, Associate Professor, Director, Maternal & Child Health Program, Milken Institute School of Public Health, The George Washington University
66. Westmoreland, Timothy M., JD, Professor from Practice, Emeritus, Georgetown University School of Law