November 13, 2023 *via Online Portal (www.regulations.gov)*

Melanie Fontes Rainer, Director

Office of Civil Rights

U.S. Department of Health and Human Services

200 Independence Avenue, SW

Washington, DC 20201

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

Dear Director Fontes Rainer:

Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to comment on the proposed rule under Section 504 of the Rehabilitation Act of 1973 (Section 504), Nondiscrimination on the Basis of Disability in Health and Human Service Programs or Activities (proposed rule), issued by the Office for Civil Rights (OCR) at the Department of Health and Human Services (HHS). We recognize how the proposed rule, in both its substance and the process of seeing input from members of the disability community, builds upon the original regulation which was achieved because of direct action from people with disabilities and developed through respectful and cooperative stakeholder relationships established between representatives from HHS and the disability community.

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. In the more than 40 years that have passed since our founding, we have persistently fought for the right of people with disabilities to be fully integrated within all aspects of community life. DREDF's work is based on the knowledge that people with disabilities of varying ages, racial and ethnic backgrounds, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law.

DREDF supports OCR’s updates and clarifications of disability discrimination protection in the proposed rule. We strongly agree that the recent COVID-19 pandemic exposed long-standing barriers to equally effective healthcare for disabled people and embedded ableism in the healthcare profession. We contributed to and endorse detailed comments on the proposed rule from the Consortium for Constituents with Disabilities (CCD). We also endorse the comments of the Partnership to Improve Patient Care (PIPC) in its detailed discussion of Value Assessment (§ 85.57) that inherently downgrade the length, quality, and worth of disabled lives. In our own comment, we are raising the additional points below to provide OCR with additional information, resources, and recommendations on specific topics raised in the proposed rule so that they can be considered as the rule is finalized and timely passed into law. The topics are covered below in their order in the proposed rule.

**Section 84.4(a) - Disability**

*Obesity*

We strongly support OCR’s proposal to incorporate the definition of disability from the Americans with Disabilities Act such that the breadth of the term and its intended construction under the Americans with Disabilities Act Amendment Act (ADAAA)[[1]](#endnote-1) are incorporated within Section 504. We also strongly support the recognition of Long COVID with the proposed rule’s non-exhaustive list of physical or mental impairments, given the significant percentage of the population that now experiences Long COVID as a chronic disabling condition and because the condition did not exist at the time of the original 504 regulation. That same reasoning should persuade the OCR to seriously consider the inclusion of obesity within the list of physical or mental impairments. While higher weight people existed during the 1970s and obviously well before, the medical fields understanding of obesity as a medical condition or “disease” that requires active treatment, even without any accompanying comorbidities, has changed sharply since Section 504, the ADA, and even the ADAAA was enacted.[[2]](#endnote-2) This shift has been accompanied by a move away from the new of higher weight as individuals who lack willpower and are entirely responsible for their own presumed ill health which can be reversed with simple exercise and better eating habits.

Unfortunately, this change in the perception of higher weight, obesity, and the personal characteristics of higher weight people has not been accompanied by a reduction in the pervasive healthcare discrimination endured by higher weight individuals. The presence of higher weight is treated as a disabling condition for the purposes of *denying* health care and treatments such as organ transplants or fertility treatments, yet not acknowledged as a disability when it comes to needed protection from medical treatment discrimination, barriers of inaccessible equipment, unequal care, and still existing stereotypes. DREDF endorses the many examples of healthcare discrimination raised by Fat Legal Advocacy, Rights and Education (FLARE!) in its comment to HHS OCR on the proposed rule. FLARE’s point that higher weight is more prevalent among people of color, and among some members of LGBTQ+ communities, also means that some disabled individuals are facing the burden of compounded layers of discrimination when seeking healthcare, and left without the legal tools that allow them to seek redress for denials of care and inaccessibility that are extremely difficult to disentangle as “solely” attributable to a recognized disability, obesity, the color of their skin, or their gender identity or sexual orientation. While the following recommendations may not fully address all of these problems, they will at least begin to level the playing field for higher weight people who are already recognized medically, and unfortunately discriminated against, as if they were disabled.

* Include “obesity” in the list of examples of physical or mental impairments, along with examples of higher weight discrimination in the healthcare and other relevant fields such as child care.
* Recognize blanket BMI cutoffs for medical treatment, including organ transplantation, as discrimination when they result in the denial of treatment or overriding of individualized medical evaluations of patients who are obese or higher weight for healthcare.
* Under **Medical Question #2** and **Medical Question #3**, the preamble should include the fact that a higher weight person has the right to choose an appropriate yet potentially less effective treatment, rather than be outright denied treatment, or forced to undergo a delay in treatment to undergo treatment “optimization” through weight loss attempts which are often not successful for the average person.
* Just as the CCD recommends that HHS work with the Access Board to develop accessible standards for medical equipment of all kinds for people with non-mobility disabilities, including equipment designed for use at home, HHS’s work in this regard must encompass ongoing gaps in the Access Board’s MDE standards that are not fully inclusive of the needs of people of all sizes, including higher weight persons. In this recommendation, across all groups of disabled people, we strongly recommend the Access Board’s use of a full stakeholder process that includes representatives from the higher weight community, the blind community, and others who best understand both the ongoing barriers they encounter and the best means of overcoming those barriers and discriminatory attitudes.

*Chemical and Electromagnetic Hypersensitivities*

The proposed rule does not mention individuals with chemical and electromagnetic hypersensitivities, but their access to healthcare for the most common conditions from a toothache to setting an injured limb to receiving treatment for COVID-19 can be extremely curtailed by their disability, even when their disability is accompanied by clear comorbidities such as a seizure disorder or other neurological responses triggered by exposure to environmental toxins and conditions. Straightforward requests for accommodation such as waiting outside for an appointment to minimize exposure to interior fragrances and WiFI are commonly denied, much less accommodations that are a little more involved but nonetheless very possible such as cleaning one exam room without harsh chemicals or scents for an early morning appointment and temporarily unplugging air fresheners. In addition, metal shielding that would from electromagnetic fields that accompany needed durable medical equipment such as electric wheelchairs or scooters could be made available for purchase or rental. DREDF recommends that HHS and the Access Board engage with people with chemical and electromagnetic sensitivities to understand their healthcare needs and the barriers to healthcare that they endure and make it clear that when such hypersensitivities arise to the level of a disability, healthcare providers must provide reasonable accommodations and policy modifications.

**Subpart C—Program Accessibility**

**§ 84.22 Existing facilities.**

(a) General. A recipient shall operate each program or activity so that the program or activity, when viewed in its entirety, is readily accessible to and usable by individuals with disabilities.

This paragraph does not—

(1) Necessarily require a recipient to make each of its existing facilities accessible to and usable by individuals with disabilities;

DREDF recommends against the inclusion of the above language from Title II of the ADA within the Section 504 rule. The program accessibility requirement was designed with state, county, and municipal services in mind, which often are housed in historic buildings and are providing services that are basically fungible. At least two factors in the healthcare space differ markedly from the scenario envisioned in Title II of the ADA. First, the healthcare arena over the past two or three decades has been marked by a growing propensity to horizontal and vertical consolidation. Hospitals merge, acquire smaller provider practices and specialty clinics, and are in turn acquired by larger regional and national healthcare entities. The result, as investigations show, have generally lead to *higher* healthcare prices and no evidence of increased quality.[[3]](#endnote-3) For people with disabilities, consolidation could theoretically lead to improved accessibility if, for example, corporate entities use their buying power to buy accessible medical equipment in larger quantities, give manufacturers greater reason to develop accessible medical equipment, and assist small practices, especially those that offer LEP languages or that work with health disparity populations, to turnover medical equipment and gain training in disability cultural competency. Unfortunately, the application of the program accessibility concept to an industry that is consolidating and making record profits incentivizes against such increases in accessibility if, for instance, a corporation could argue that among its three hospitals in a given city, it can enhance accessibility and healthcare services in *one* of those hospitals, or in only *some* of its clinics, to ensure overall program access. The second factor that speaks against the application of program access in healthcare is the simple fact that healthcare providers are not fungible. Patients with disabilities, who may typically require more healthcare services for longer periods, develop relationships and trust with specific providers and care teams, possibly on the basis of other personal factors such as language, sexual orientation, or gender identity. Those relationships should not be put at risk by corporate healthcare acquisitions that may make overall program access decisions without prioritizing care continuity, patient choice, or stakeholder consultation.

**§ 84.23 New Construction and Alterations.**

The existing Section 504 regulations has applied now for 45 years. Clearly, the state of the art accessible construction standards that applied in 1978 have come a long way. As we look at the language to clarify and align Section 504 of the Rehabilitation Act with other standards addressing accessible facilities, DREDF recommends that HHS OCR adopt the most current standard that currently exists because this is a standard that is likely to apply into future decades. The International Building Code 2021 Chapter 11 and ICC A117.1 in its entirety provides greater overall accessibility to people with disabilities and a higher level of buildings and facilities accessibility standard than the 2010 ADA standard. The 2010 ADA Standard was written in 2004 and adopted by DOJ in 2010. The language in the ADA standard is therefore based on knowledge and anthropometrics from 19 years ago.

The ICC A117.1 (2017 edition) Accessible and Usable Buildings and Facilities is a

standard developed by the International Code Council through a consensus process

approved and monitored by the American National Standards Institute to provide

technical criterial to make sites, facilities, buildings and elements accessible to and

usable by people with physical disabilities.[[4]](#endnote-4) The intent of these sections is to allow a

person with a physical disability to independently get to, enter, and use a site, facility,

building or element. The ICC 2017 edition includes enhanced dimensions for turning spaces and clear floor spaces to accommodate wheeled mobility devices based on

anthropometric data that has been published in the years since the passage of the 2010

ADA. Additional changes include features allow for better communication for persons

using sign language, revised parking and loading zone criteria, enhanced exterior route

information and safety for crossing parking lots and the addition of water bottle filler

criteria, to name only a few details.

If the ICC A117.1 is paired with the scoping language found in the 2021 International Building Code Chapter 11, which is similar to the 2010 ADA but is more effectively aligned to point to the standards in the ICC A117.1. Together they address the same breadth of information as the 2010 ADA but with more current anthropometrics. Moreover, the IBC Chapter 11 and ICC A117.1 are already utilized in the majority of states as Building code requirements so the alignment with current construction requirements should be quite seamless.

As a result, we recommend that the reference to the 2010 ADA in the proposed rule be

replaced as follows -

§ 84.23

New construction and alterations.

(c) Accessibility standards and compliance dates for recipients that are public entities.

(5) If physical construction or alterations commence on or after [DATE ONE YEAR

FROM PUBLICATION DATE OF FINAL RULE IN THE FEDERAL REGISTER ], then

new construction and alterations subject to this section shall comply with the ~~2010~~

~~Standards.~~ International Building Code 2021 Chapter 11 and ICC A117.1 in its entirety.

(d) Accessibility standards and compliance dates for recipients that are private

entities. (3) Newly constructed or altered facilities or elements covered by paragraph (a)

or (b) of this section that were constructed or altered before [DATE ONE YEAR FROM

PUBLICATION DATE OF FINAL RULE IN THE FEDERAL REGISTER ] and that do not

comply with ANSI (for facilities constructed or altered between June 3, 1977, and

January 18, 1991) or UFAS (for facilities constructed or altered on or after January 18,

1991) shall, on or after [DATE ONE YEAR FROM PUBLICATION DATE OF FINAL

RULE IN THE FEDERAL REGISTER ], be made accessible in accordance with the

~~2010 Standards.~~ International Building Code 2021 Chapter 11 and ICC A117.1 in its

entirety.

**§ 84.56: Medical Treatment**

* *Medical Treatment Question 5: The Department also seeks comment on whether the term ‘‘medical treatment’’ adequately encompasses the range of services that should be covered under this nondiscrimination provision.*

Reproductive Care for People with Disabilities

In light of the Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Org*. that stripped Americans of their established right to abortion care, and the multiple state abortion bans and limitations on access to reproductive care that soon followed, DREDF seeks to highlight the explicit application of these rules to the reproductive health care space and the inclusion of full reproductive health care services as a vital component of “medical treatment.” DREDF endorses the Sexual and Reproductive Health, Rights, and Gender Justice community comments that highlight important considerations for the Department at the intersection of reproductive justice and disability justice. One additional consideration we wish to raise here is the application of the rules to the provision of abortion care under medical emergency exceptions to state-specific abortion bans. Although people with disabilities get pregnant at similar rates as non-disabled people, they are at higher risk than nondisabled people for severe maternal morbidities and maternal mortality once pregnant. *See* Willi Horner-Johnson, *et al.*, *Pregnancy among U.S. Women: Differences by Presence, Type, and Complexity of Disability*, 214(4) Am. J. Obstet. & Gynecol. 529e.1, 529e.8 (Apr. 2016) (describing evidence that people with disabilities face increased risks of health problems during pregnancy and poorer pregnancy outcomes); *see also*  Jessica Gleason et al., *Risk of Adverse Maternal Outcomes in Pregnant Women with Disabilities*, JAMA Network Open (2021), <https://tinyurl.com/58fxzvh9> (reporting findings that women with disabilities had higher risk of maternal mortality and all severe maternal morbidities, including severe preeclampsia/eclampsia, hemorrhage, fever, thromboembolism, cardiovascular events, and infection than non-disabled people). As such, people with disabilities need access to abortion under the medical exceptions to abortion bans at a higher rate than non-disabled people. Exceptions that are ambivalent or unclear in affording doctors the ability to provide abortions as they deem necessary in their professional and good faith judgment, to preserve the health or protect the life of the pregnant person, discriminate against people with disabilities by disproportionately placing pregnant people with disabilities at risk of death and negative outcomes.

**§ 84.92(a): Requirements for newly purchased, leased, or otherwise acquired medical diagnostic equipment**

* *MDE Question 5: The Department seeks public comment on whether the proposed approach to dispersion of accessible MDE is sufficient to meet the needs of individuals with disabilities, including the need to receive different types of specialized medical care.*

We share the CCD comment’s commitment and recommendation of achieving 100% medical equipment accessibility with the turnover and acquisition of new equipment, whether by purchase, rental, lease, or any other arrangement such as trade-in. However, in the interim period during before 100% accessible medical equipment has been achieved, DREDF recommends dispersion requirements for accessible weight scales, exam tables, and other medical equipment be applied to every department, unit, provider, or other subpart of a larger entity such as a hospital or hospital system that has the capacity to manage its own booking system. That is, a large “optical department” or facility that encompasses opticians, ophthalmologists, a glasses retailer, and additional specialists should have a minimum complete set of accessible equipment for each unit within the department that is booking patients. Otherwise, the sharing of medical equipment, even if it can be transferred between booking units, will be a logistical nightmare and lead to inevitable delays and conflicts between patient use.

Where equipment cannot be transferred relatively easily between adjacent units, additional problems can arise where the departments are not functionally serving the same medical purpose, even if they are related purposes. An ophthalmologist or specialist in macular degeneration, to continue using the same example, may have other specialized equipment in their office for diagnostic or treatment purposes that can actually be used without the need for modification, but it is not ready to hand if the ophthalmologist must go to a central location to access one or two accessible diagnostic chairs that opticians also use. In addition, the privacy of a disabled patient is as valuable as the privacy of any other patient. No patient should be required to undergo medical examination elements in a shared central space just because they have a mobility or other disability.

• *MDE Question 14: If this rule were to apply to medical equipment that is not used for diagnostic purposes,*

* ‘‘*Should the technical standards set forth in the Standards for Accessible Medical Diagnostic Equipment be applied to non-diagnostic medical equipment, and if so, in what situations should those technical standards apply to non-diagnostic medical equipment?*’’
* *Are there particular types of nondiagnostic medical equipment that should or should not be covered?*

DREDF, in concert with CCD, strongly supports the inclusion of a range of medical equipment, including equipment used primarily and only for treatment, within the proposed rule’s requirement of equipment accessibility. People with disabilities would otherwise be stuck in the situation of being able to know what their health problem is but unable to access the equipment needed to treat that condition equally and effectively. However, we do appreciate that HHS OCR is not in the position of having expertise to simply impose technical requirements on a range of treatment and therapeutic equipment. Furthermore, DREDF is cognizant that the rapid pace of technological innovation in medicine and more generally can lead to healthcare treatments, treatment delivery methods, and treatment equipment that we can hardly imagine now. In such cases of innovation, it becomes critical for people with disabilities to be involved in the beginning of equipment design and not only as an afterthought; we have seen this occur already in various fields from automated driverless vehicles to automated decision-making systems. The early consideration of accessibility in design can make crucial differences in how and when people with disabilities can access a revolutionary new therapy or treatment, and this applies equally to treatments and therapies that incorporate existing technologies such as smart phones or Apple watches as a means of monitoring or sharing information with healthcare providers.

DREDF recommends that HHS OCR consider incorporating a greater standing directive in its relationship with the Access Board to engage in ongoing standard-making in the area of medical equipment. This is a relationship that would extend beyond membership in the Access Board, and involve cooperation in developing and disseminating universal design standards in medical equipment. HHS OCR, of course, will retain its own discretion to enact enforceable regulatory standards by deciding whether and when to adopt medical equipment standards that are created through the Access Board’s consensus building process and consultation with experts and stakeholders from the medical, scientific research, and disability community. But establishing a framework beforehand for “universal design” standards that can be applied to medical diagnostic, exam, and treatment equipment will ensure that people with disabilities have faster greater access to innovative medical care.

**Additional Overarching Considerations**

*Additional Regulatory Language and Guidance on the Phrase “Solely by Reason of Her or His Disability”*

In recent years, the phrase “solely by reason of his or her disability” found in Section 504 has become a textual battleground in cases that threaten to gut disability civil rights. Despite the reasoning by the Supreme Court in Alexander v. Choate, 469 U.S. 287 (1985), the nature of disability discrimination, and the text of the 1977 regulations – adopted with the oversight and approval of Congress – and dozens of other agency rules, lawyers for Section 504 and Section 1557 defendants claim that the phrase means that only intentional discrimination is prohibited, and that other forms of discrimination are not actionable under the law.[[5]](#endnote-5) The “solely” arguments persist, even though the design of systems that discriminate against and exclude people with disabilities is inherently intentional. Cf. Schmitt v. Kaiser Found. Health Plan of Wash., 965 F.3d 945, 954 (9th Cir. 2020). The disability community has expended extraordinary resources fighting this false and ahistorical construction of Section 504.  
  
If successful, these arguments would devastate the scope of prohibited disability discrimination. “Discrimination against the handicapped was perceived by Congress to be most often the product, not of invidious animus, but rather of thoughtlessness and indifference – of benign neglect.” Alexander v. Choate, 469 U.S. 287, 295-96 (1985). A sidewalk without a ramp denies access to a person in a wheelchair, regardless of intent. Congress in Section 504 of the Rehabilitation Act of 1973 sought to remedy just such discrimination.  
  
The Agency’s proposed regulations include the phrase within proposed Section 84.68(a) but include no additional regulatory language defining the language. See 88:177 Fed. Reg. at 63505 (“No qualified individual with a disability shall, solely on the basis of disability, be excluded from participation in or be denied the benefits of the programs or activities of a recipient, or be subjected to discrimination by any recipient.”). The proposal does include helpful language in the introductory material, which states: “As used in this part, solely on the basis of disability is consistent with, and does not exclude, the forms of discrimination delineated throughout the rule. 88:177 Fed. Reg. at 63473; see also id. at 63474 (containing helpful discussion of Alexander v. Choate).  
  
We ask that the Agency provide additional regulatory language and guidance on the phrase “solely by reason of his or her disability” that reflects case law, statutory purpose, and Congressional action. For example, the regulations could include text such as:

“Solely on the basis of disability” means that there is a demonstrable relationship between the discrimination alleged and the disability.  
  
As used in this part, “solely on the basis of disability” includes the forms of discrimination delineated herein, including discrimination that results from thoughtlessness, indifference, and benign neglect, practices that have the effect of discrimination, and unintentional disparate-impact discrimination.  
  
“Solely on the basis of disability” shall not be construed to lead to or require anomalous results, such as excluding claims where nondiscrimination requires the expenditure of funds, as such expenditure was clearly contemplated by the statute, or where the cited basis for discrimination cannot be extricated from the disability itself.

It would be enormously helpful for the Agency to provide regulatory language that explicitly defines and clarifies the statutory phrase in favor of broad coverage, as Congress intended.  
  
The Agency should also include additional contextual language in the regulatory guidance. For example, the Agency could add content similar from that contained in the United States’ amicus brief in CVS v. Doe, No. 20-1374 (U.S. Oct. 28, 2021). That brief properly notes that the language in Section 504 is written in the passive voice and makes no reference to any specific actor or intent. Thus, the phrase “is most naturally read to focus on the causal link between the plaintiff’s disability and particular undesired effects, rather than on the motives or intent of the defendant.” Id. at 6-7. “A student who uses a wheelchair and is unable to reach an auditorium that is accessible only by stairs, for example, is naturally described as ‘being excluded from the assembly solely by reason of his disability.’” Id. at 7. The brief also reasons that, following consistent court of appeals decisions and agency regulations that have recognized disparate-impact liability, Congress “specifically reconfirmed the Rehabilitation Act’s focus on full integration in subsequent amendments to the Act.” Id. Further, the brief explains, “[i]nterpreting Section 504 to require a showing that the defendant took a particular action because of, not merely in spite of, its effect on individuals with disabilities would prevent the Act from reaching core applications that Congress sought to cover.” Id. at 7. Including this type of context in the regulatory guidance would be enormously helpful to people with disabilities facing an unwarranted textual argument.

*Relationship to Section 1557*

Section 1557 of the Affordable Care Act is the most important and specific nondiscrimination provision operating at the junction of disability rights and healthcare since the passage of the ADA. As noted in the preamble to the 2022 Notice of Public Rulemaking on Section 1557, “Title VI, Section 504, and the Age Act apply to *all* federally funded programs or activities, Section 1557 applies only to *health* programs or activities.”[[6]](#endnote-6) While Section 1557 cites to and incorporates the discrimination grounds and enforcement mechanisms available under Section 504, HHS has recognized that current regulations "provide[] no guidance on how covered entities are to implement their compliance responsibilities under Section 1557 and, in particular, whether those responsibilities are the same as, or deviate from, their compliance responsibilities under... Section 504... Rather, it generally states the nondiscrimination requirements of Section 1557 by restating the statutory language of 42 U.S.C. 18116(a), followed by stating that the grounds prohibited are the grounds found in... Section 504....The resulting uncertainty is particularly stark for procedural requirements."[[7]](#endnote-7)

Enacted 37 years after Section 504 and 20 years after the ADA, Section 1557 can and should be seen as an expression of the will of Congress concerning the right of people with disabilities to be free of discrimination in the programs or activities of entities that provide health-related services, health insurance coverage, or other health-related coverage.[[8]](#endnote-8) The wording of Section 1557 itself, which sweeps in “credits, subsidies, and contracts of insurance” as forms of federal financial assistance, broadcasts its intent to require nondiscrimination of health insurance issuers and not only the health service providers that have traditionally been the focus of Section 504 and the ADA. Moreover, the Secretary of HHS is given authority to enact regulations for the interpretation, monitoring, and enforcement of both Section 1557 and Section 504. Since the current proposed rule is intended to update and clarify the operation of Section 504 in light of key legislation, cases, and world events such as the COVID-19 pandemic, we strongly urge OCR to further parse out in this proposed rule how Section 504 and Section 1557 work together to protect people with disabilities from common discriminatory barriers that arise across multiple types of healthcare entities that function in the complex US healthcare system.

We recommend that HHS OCR incorporate provisions that will explicitly recognize the purpose and intent of the following nondiscrimination sections from the 1557 NPRM and apply them to the “broader range of programs and activities by recipients of Federal financial assistance”[[9]](#endnote-9) that fall under Section 504, including insurance issuers.

### The Use of Automated Decision-Making Tools and Systems

Disability-related bias can be incorporated in a wide range of automated decision-making tools formally and informally used by issuers of health and health-related coverage, but they can equally play important roles in the systemic procedures, policy-making, and individual patient/client/enrollee decisions made by recipients of federal financial assistance. For example, child welfare agencies may use predictive algorithms or clinical decision trees that rank a parent or child’s disability as a factor for taking away custody or denying reunification services, but those tools are operating on the level of simple statistical correlation without any individualized analysis of whether or how a family member’s specific disabilities and the potential for disability-related supports affect the child’s wellbeing.

Similarly, clinical guidance tools that point to the existence of multiple providers as a predictive risk-factor for opioid abuse fail to consider how people with multiple and significant disabilities will have multiple healthcare providers.[[10]](#endnote-10) In another example, the historic and ongoing lack of functional disability data in health records means that decision-making tools and systems have not been adequately trained to recognize how factors such as the use of personal care assistance are inadequately recognized in the allocation of home and community-based services and supports, including care coordination. Language in regulations enacted under Section 504 does not have to simply echo proposed language for a Section 1557[[11]](#endnote-11) rule given the broad reach of Section 504 and recipients who engage in multiple kinds of decision-making, from medical treatment to family interventions to benefit eligibility and coverage.

We recommend that HHS explicitly clarify that prohibitions on discrimination already contained in the proposed rule, such as those found at (§ 84.68(b)(8)) and (§ 84.60(c)), fully encompass situations that involve some use of automated decision-making tools and systems and take the opportunity to clarify that the employment of automated decision-making tools and systems by recipients must be transparent and readily subject to appeal.

### Benefit Design and Related Concepts

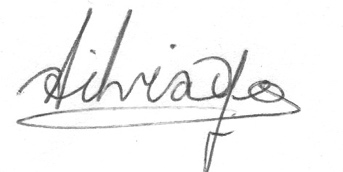
The preamble to the proposed rule states that “this rule does not relate to benefit design or other health insurance coverage issues.”[[12]](#endnote-12) However, benefit design does not only conceptually apply to health insurance coverage. The design and delivery of health and health-related services is greatly impacted by multiple factors such as the quality and depth of provider networks, the use of utilization management tools, the use of automated decision-making tools and systems, the choice and application of equity and quality measures, how service denials can be appealed, how patient data is recorded and aggregated, and so forth. Conceptually, it can be difficult to distinguish where “benefit design” ends and where these myriad aspects of service delivery and accessibility begin, but Section 504 must be able to reach the many barriers for people with disabilities that can be embedded in all these different facets of health and human service delivery. There is no reason to disavow benefit design from the reach of the proposed rule, and every reason to follow the proposed Section 1557 rule's lead in embedding key aspects of the proposed rule such as the integration mandate as a required aspect of all these related concepts. We recommend modifying the assertion in the preamble that the proposed rule does not relate to benefit design, or deleting it altogether.

### Collection of Functional Disability Data for Demographic Purposes

Section 1557 does not directly address disability demographic data collection in electronic health records or administrative forms, but the consistent provision of needed individual accommodations and the full inclusion of disabled people within burgeoning health equity and quality initiatives cannot take place without such data collection. The recognition of the need for and importance of disability demographic data to nondiscrimination protections is especially timely when the common acquisition, sale, storage, and unregulated use of Big Data makes it possible to impute disability to individuals who then face negative repercussions, but those same individuals are then excluded from granular healthcare disparities analyses and equity initiatives that would help ensure their equal access to healthcare.[[13]](#endnote-13) We recommend including a provision in the proposed rule that would require recipients to gather disability demographic information that would allow for the equal inclusion of people with disabilities in equity and quality analyses, including information on whether and how people with disabilities received accommodations needed for equally effective medical treatment.[[14]](#endnote-14)

Thank you again for the opportunity to comment on the proposed rule. Please feel free to contact us if you have any questions about our responses to select sections of the rule or any recommendations we have made above.

Sincerely,

****

Silvia Yee

Senior Staff Attorney

1. Public Law 110–325 (2008). [↑](#endnote-ref-1)
2. American Medical Association, Council on Science and Public Health, [Recognition of Obesity As a Disease H-440.82](https://policysearch.ama-assn.org/policyfinder/detail/obesity?uri=%2FAMADoc%2FHOD.xml-0-3858.xml) (2023). *See* also The Obesity Society, “[Obesity as a Disease: the Obesity Society 2018 Position Statement](https://www.obesity.org/wp-content/uploads/2019/04/Jastreboff_et_al-2019-Obesity.pdf),” (2019) (characterizing obesity as a “non-communicable chronic disease”). [↑](#endnote-ref-2)
3. Karyn Schwartz, Eric Lopez, Matthew Rae, and Tricia Neuman, “[What We Know About Provider Consolidation](https://www.kff.org/health-costs/issue-brief/what-we-know-about-provider-consolidation/),” Kaiser Family Foundation, (Sept. 2, 2020). [↑](#endnote-ref-3)
4. The National Technology Transfer Advancement Act requires federal agencies to use consensus standards when they meet an agency's needs.  See OMB Circular at 119 (<https://www.whitehouse.gov/wp-content/uploads/2020/07/revised_circular_a-119_as_of_1_22.pdf>) and this summary of the Act with links to the law (<https://www.epa.gov/laws-regulations/summary-national-technology-transfer-and-advancement-act>).  [↑](#endnote-ref-4)
5. See, e.g., Opening Brief of CVS in CVS v. Doe, No. 20-1374 (U.S. Sept. 3, 2021) 10-11 (“The statutory text unambiguously forecloses disparate-impact liability. … Section 504 requires that the discrimination be ‘solely by reason of’ disability. … [T]hat language imposes a sole-causation requirement. That requirement cannot be squared with regulating disparate impacts, which almost always arise from diverse causes. Section 504 also focuses on the “individual” being treated differently, not on a group experiencing disparate effects.”); ECF 415 in Payan v. Los Angeles Cmty. College Dist., No. 2:17-cv-01697 (C.D. Cal. Jan. 3, 2022) (requesting continued stay to provide opportunity to request Supreme Court review of whether private cause of action for disparate impact discrimination exists); Doe v. BlueCross BlueShield of Tenn., Inc., 926 F.3d 235, 242 (6th Cir. 2019) (“Disparate-impact discrimination occurs when an entity acts for a nondiscriminatory reason but nevertheless disproportionately harms a protected group. … But the Rehabilitation Act bars discrimination ‘solely by reason of her or his disability.’ … That language does not encompass actions taken for nondiscriminatory reasons.”); cf. Payan v. L.A. Cmty. Coll. Dist., Nos. 19-56111, 19-56146, 2021 U.S. App. LEXIS 25336, at \*9 (9th Cir. Aug. 24, 2021) (Lee, J., dissenting). [↑](#endnote-ref-5)
6. 87 Fed. Reg. 47844. [↑](#endnote-ref-6)
7. 87 Fed. Reg. 47830. [↑](#endnote-ref-7)
8. 87 Fed. Reg. 47912, proposed definition of “Health program or activity.” [↑](#endnote-ref-8)
9. 88 Fed. Reg. 63483. [↑](#endnote-ref-9)
10. Maia Szalavitz, [*The Pain Was Unbearable, So Why Did Doctors Turn Her Away?,*](https://www.wired.com/story/opioid-drug-addiction-algorithm-chronic-pain/)WIRED (Aug. 11, 2021). [↑](#endnote-ref-10)
11. 87 Fed. Reg. 47918, see § 92.210 for example. We note, however, that we would welcome an approach in the final Section 1557 rule that prohibits disability bias more generally across automated decision-making tools and systems. [↑](#endnote-ref-11)
12. 88 Fed. Reg. 63483. [↑](#endnote-ref-12)
13. S. Yee & M.L. Breslin, *Risks and Rewards of Demographic Data Collection: How Effective Data Privacy Can Promote Health Equity*, March 2023, <https://healthlaw.org/wp-content/uploads/2023/03/This-Data-Not-That-Data_Disability-Rights-Education-and-Defense-Fund_FINAL.pdf>. [↑](#endnote-ref-13)
14. M.L. Breslin and S. Yee, Demographic Disability Data Brief, forthcoming. [↑](#endnote-ref-14)