



October 3, 2021

Melanie Fontes Rainer
Director
Office of Civil Rights
Department of Health and Human Services

**Re: Notice of Proposed Rulemaking: Docket ID: HHS–OS–2022–0012, RIN:
0945–AA17, Nondiscrimination in Health Programs and Activities**

Dear Director Fontes Rainer:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Health Care, Long Term Services and Supports, and Rights Task Forces write to comment on the notice of proposed rulemaking referenced above. CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

CCD commented on both prior 1557 proposed rules because of the importance of non-discrimination protections for people with disabilities.¹ People with disabilities face substantial disparities in access to health care and frequently face discrimination in access as our prior comments and these comments discuss. The pandemic unfortunately highlighted several forms of concerning discrimination against people with disabilities, including in care rationing and disproportionate death rates for the disproportionate number of institutionalized people with disabilities.² This rule would

¹ CCD Comments (Nov. 9, 2015), <https://c-c-d.org/fichiers/1557-CCD-comments-10-28-15-for-sign-on.pdf>; CCD Comments (Aug. 13, 2019), <https://www.c-c-d.org/fichiers/CCD-1557-Comments-FINAL.pdf>.

² Joseph Shapiro, NPR, *One Man's Covid-19 Death Raise the Worst Fears of Many People with Disabilities* (July 31, 2020), <https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities>; United Nations, *Policy Brief: A Disability-Inclusive Response to Covid-19* (May 2020), <https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-A-Disability-Inclusive-Response-to-COVID-19.pdf>; Priya Chidambaram, Kaiser Family Found., *Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died From Covid-19* (Feb 3., 202), <https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/>; <https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/>

begin to address several of those issues in addition to reinstating provisions we strongly supported in the 2016 rule, including clear protections for those with disabilities who are also people of color, LGBTQ+, and other marginalized identities.³ We support this rule and urge CMS to finalize it quickly. We have a few clarifying questions and suggestions detailed below.

Our comments are organized by section.

SUBPART A

§ 92.1 – Purpose and Effective Date

We strongly support the effective date of 60 days after publication of the final rule. While we understand the reasons for the exception for health insurance and group health plans to allow for revisions to their products related to benefit design and the changes proposed regarding Medicare Part B, we believe that any delay beyond the exception proposed in the rule would be extremely harmful for people with disabilities and other marginalized communities who are being protected by the revisions in the rule. We urge CMS to finalize this section as proposed.

§ 92.2 – Application

We also strongly support the reinstatement of the 2016 rule’s interpretation of “health programs and activities” and the application of the section to recipients of Federal financial assistance. As we commented in 2019, we believe that the 2019 rule misread clear statutory language, that Section 1557 does not incorporate the Civil Rights Restoration Act, and that the new interpretation inappropriately narrowed the scope of Section 1557.⁴

§ 92.4 - Definitions

We strongly support HHS reinstating a definitions section. We agree that the lack of a specific set of definitions contributes to uncertainty and we strongly opposed the elimination of this section in 2019.

³ We are aware that revised regulations on Section 504 are also being developed by the Office of Civil Rights. CCD wrote to the Department about our priorities in that regulation and look forward to commenting on it soon. Letter from CCD on Section 504 Regulations (Apr. 26, 2022), https://www.c-c-d.org/fichiers/FINAL_CCD-504-Letter_4-26-22.pdf.

⁴ CCD Comments (Aug. 13, 2019) at 4-5, <https://www.c-c-d.org/fichiers/CCD-1557-Comments-FINAL.pdf>.

A. Auxiliary Aids and Services

We support HHS's proposal to incorporate the definition of "auxiliary aids and services" from the Americans with Disabilities Act (ADA) regulations.⁵ We recommend that the text clarify that "similar services and actions" are available for all individuals with disabilities, not just for deaf and hard of hearing individuals and blind and low vision individuals referenced in subsections (1) and (2).

RECOMMENDATION: Amend the definition of auxiliary aids and services as follows, to clarify that "similar services and actions" are available for all individuals with disabilities.

(4) Staff acting as interpreters: A covered entity must not use staff who use sign language or another communication modality⁶ to act as interpreters and relay information to individuals with disabilities unless

***a) they meet the definition of a qualified interpreter for an individual with a disability found within this section; and
b) meet the unique needs of the individual requesting the accommodation; and***

(5) Other similar services and actions that support people with disabilities in effective communication.

B. Companion

We appreciate the inclusion of the definition of the term "companion," and HHS's explanation that a companion may include a "family member, friend, or associate of an individual. . ." who is "an appropriate person with whom a covered entity should communicate."⁷ We note, however, that the determination of who is appropriate must lie with the individual with a disability (or their designated decision-maker pursuant to state law), and not with the provider. Deferring to the individual with a disability to determine who is their companion or appropriate person to communicate with is critically important as providers communicating directly to non-designated companions may not only violate privacy laws, but undermines the autonomy of people with disabilities. We suggest that

⁵ 28 C.F.R. § 35.104; 28 C.F.R. § 36.303(b).

⁶ Throughout these comments we use the term "communication modality" to refer to a variety of ways interpreters may communicate with clients, including, for example, cued speech transliteration or oral transliteration. We recognize that ASL interpreters, for example, are translating from one language to another, while other types of interpreters may be transliterating spoken English into a method of communication that facilitates understanding for an individual with a disability. In these cases, we are using the term communication modality in instances where the interpreter is not translating between two different languages.

⁷ 87 Fed. Reg. 47911.

HHS add language to clarify that the determination of who is “appropriate” lies with the individual, not with the provider.

C. Qualified Interpreter for an Individual with a Disability

We support HHS’s proposal to incorporate the definition of “qualified interpreter for a person with a disability” from the ADA.⁸ However, we suggest closer alignment between the definitions related to qualified interpreter for a limited English proficient individual (LEP) and qualified interpreter for an individual with a disability. We believe all interpreters should demonstrate proficiency in either a) communicating and understanding both English and a non-English language (including American Sign Language, other sign languages) or b) proficiency in another communication modality (such as cued speech or oral transliteration). Additionally, all interpreters should interpret “without changes, omissions, or additions and while preserving the tone, sentiment, and emotional level of the original statement and [also] adhere. . . to generally accepted interpreter ethics principles including client confidentiality.”⁹ Alignment of the standards should decrease confusion for covered entities, increase the likelihood that all interpretation will be provided with sufficient standards and meet the requirements, and increase the likelihood that all people who need interpretation or access to auxiliary aids and services will have the access to care they need.

RECOMMENDATION: Amend the definition of qualified interpreter for an individual with a disability as follows:

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

- (1) *Has demonstrated proficiency in communicating in, and*
a) understanding, both English and a non-English language
(including American Sign Language, other sign languages); or
b) another communication modality (such as cued-language
*transliterations or oral transliteration).*¹⁰**

⁸ 28 C.F.R. §§ 35.104; 36.104.

⁹ 87 Fed. Reg. 47913.

¹⁰ We note that not all interpreters for people with disabilities are translating between English and another language. In some cases, they are acting as transliterators, interpreting from one communication modality into English. Another example would be Certified Deaf Interpreters, who are individuals who are deaf or hard of hearing and may be interpreting between an individual who is deaf and uses a unique version on ASL or foreign, or home signs unfamiliar to the medical interpreter. See, e.g., Registry of Interpreters for the Deaf, *Certified Deaf Interpreter* (CDI), <https://rid.org/rid-certification-overview/available-certification/cdi-certification/>.

- (2) Is able to interpret effectively, accurately, and impartially, both receptively and expressively, using any necessary specialized vocabulary ***or terms without changes, omissions, or additions and while preserving the tone, sentiment, and emotional level of the original statement; and***
- (3) ***adheres to generally accepted interpreter ethics principles including client confidentiality.***

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

§ 92.7 – Designation and Responsibilities of a Section 1557 Coordinator

We appreciate the provision that covered entities must have a designated Section 1557 coordinator. HHS requests comment on whether this provision should apply to entities with fewer than 15 employees and we recommend that the answer be yes. Even in smaller covered entities, it is essential that someone is responsible for coordinating implementation of Section 1557 including developing the required policies and procedures, ensuring relevant employees are trained, receiving and addressing grievances, and informing individuals of their rights when they interact with the covered entity. There will not be a one-size-fits-all solution and a smaller entity would not have to have a full time coordinator. But we believe it is critical that all covered entities have a designated person to ensure compliance with the law and these regulations.

Individuals with disabilities often receive additional services from smaller providers and practices. Many HCBS providers have less than 15 full-time employees. The small size of these providers allow for the flexibility needed to customize services in the least restrictive setting, as opposed to larger institutional facilities. The decision to receive service from a smaller provider should not impact their right to be free from discrimination. While preventing discrimination is critical in all health care settings, having a coordinator to ensure that Section 1557 is implemented is essential to daily life for someone who resides at a covered entity or receives HCBS, as the harm of discrimination can be amplified when it takes place where someone has to live, eat, and sleep.

§ 92.8 – Policies and Procedures

We strongly support the provisions requiring covered entities to adopt Section 1557 policies and procedures and to ensure their employees are trained on them. We agree with HHS that both employees in “public contact” positions and those who make decisions about these policies and procedures should receive training so they understand the requirements of Section 1557. We hope that such policies and procedures will ensure that covered entities are better able to meet the requirements of

Section 1557.

It is particularly important for covered entities to be proactive in their thinking and planning when developing policies and procedures to enforce Section 1557. Such policies and procedures are ways to elevate internal knowledge and proactive implementation of civil rights among covered entities and thereby alleviate the burden placed of enforcement that occurs when enforcement is primarily reliant on complainants.

During the COVID-19 pandemic, poor planning, and inadequate policies and procedures failed many people seeking health services, including people with disabilities. At the beginning of the pandemic, the “no visitation” policies adopted almost universally among in-patient facilities provides a timely and urgent reminder of why broader and deeper awareness of civil rights is needed among health care entities. Family members, friends, and paid caregivers who provide the personal care assistance needed by people with a range of disabilities were treated as simple “visitors” and turned away by security personnel, nurses, and other health care providers. The result placed people with disabilities at grave risk of having their communication and health care needs ignored or misunderstood, left unable to equally benefit from health care services, or being forced to undergo additional invasive procedures such as restraint or the insertion of a feeding tube. The COVID-19 public health emergency only highlighted how hospitals and health care facilities of various sizes have long failed to fully integrate and operationalize civil rights laws, leaving people with disabilities, their advocates, and their family members with few or no timely options to obtain the effective communication and policy modifications necessary for good health outcomes.

While we hope that the policies and procedures mentioned in this section will help covered entities to meet the requirements of Section 1557, we are unclear whether the required policies and procedures include advance planning to identify what services might be required.

Violations of disability civil rights laws do not only occur due to animus. They can happen because of ignorance, neglect, and administrative indifference, as noted in the findings of the Americans with Disabilities Act of 1990. In the arena of health care, covered entities tend to prioritize the establishment of policies, procedures, and a “chain of command” for meeting medical regulations, viewing civil rights regulations as an inconvenient add-on obligation. Technical adherence to medical regulations does not automatically achieve **equitable** health care and more needs to be done to eliminate

embedded systemic and implicit bias.¹¹

Thus, we recommend that HHS require covered entities to develop a communications access plan that addresses both language access and accessibility for people with disabilities (including people with disabilities who are LEP). For example, the 2022 Proposed Rule discusses the need for “language access procedures” which seems to be more the “nuts-and-bolts” of how to schedule an interpreter, how to identify whether an individual is LEP, etc. But there is no requirement that a covered entity think *in advance* of what types of language services it may need. This means, in terms of language access, without gathering data about the LEP population in its service area, the entity may not be able to develop effective policies and procedures. Covered entities should also plan in advance, and prepare, to ensure they can meet the communication needs of people with disabilities, including the provision of appropriate auxiliary aids and services, such as qualified interpreters.

We also recommend a requirement to develop policies and procedures to assess the competency of bilingual/multilingual staff. These could be language proficiency assessments or other methods of ensuring that bilingual/multilingual staff are indeed qualified to provide services directly in a non-English language. These policies should also include a competency requirement for staff who will act as interpreters for or provide services to individuals with disabilities. Such individuals must demonstrate that they are competent to a) provide services in a non-English language (such as American Sign Language or other sign languages) or b) another communication modality (such as cued speech transliteration or oral transliteration). If staff are acting as interpreters to relay information, they should meet the qualifications of the term “qualified interpreter for an individual with a disability” within the meaning of § 92.4. Further, the provision on policies and procedures does not mention an expectation for ongoing evaluation or updating. As OCR notes in the 2003 LEP Guidance, “effective plans set clear goals and establish management accountability.”¹² We believe both goals and accountability are essential to ensuring effective implementation of Section 1557.

§ 92.9 – Training

We support the provision that requires training on civil rights policies and procedures for all relevant employees. We note that the preamble to the 2022 proposed rule includes a definition of “relevant employees,” asserting that HHS:

¹¹ Rohan Khazanch, Health Affairs Forefront, *Race, Racism, Civil Rights Law, And The Equitable Allocation Of Scarce COVID-19 Treatments* (Feb. 10, 2022), <https://www.healthaffairs.org/doi/10.1377/forefront.20220208.453850/>.

¹² HHS LEP Guidance, 68 Fed. Reg. at 47321.

anticipates that relevant health program and activity staff will include those involved in client and patient interactions, as well as those involved with drafting, approving, and funding policies and procedures for compliance with this part.¹³

We agree it is critical that not only individuals in “public contact” positions understand civil rights policies and procedures but also that those who make decisions about these policies and procedures understand the requirements of Section 1557. We believe the above definition reflects that and suggest that HHS should include this definition either here, or in the definitions in § 92.4.

§ 92.10 – Notice of nondiscrimination

We agree that the 2020 rule does not adequately consider the needs of people with disabilities or limited English proficiency. Providing adequate notice to beneficiaries of their ability to access language assistance services and request reasonable accommodations is essential to ensuring that such individuals can access health care services. We applaud HHS for re-establishing requirements to inform beneficiaries of their ability to obtain the services they need to access health care services. We are particularly glad to see that the notices must include details on how to file a complaint with HHS. We support the proposal for conspicuous location on the website and prominent physical location.

In order to achieve the goals of this section, the notice must be available in the languages understood by the people the notice is meant to reach. We recommend that notices be provided in plain language, including English and non-English notices. We also recommend that HHS require that the notice be available in American Sign Language (ASL). As noted by the National Association of the Deaf to HHS in comments to OCR on this section in 2015, “covered healthcare entit(ies) cannot presume that English notification is sufficient for individuals who are fluent in ASL.” Covered entities should provide the notice of nondiscrimination in ASL via video on the same webpage where the other notice of nondiscrimination content is housed and provide a link or web address to this page in the prominent physical location where the other notices of nondiscrimination and notices of availability are posted. Notice must be posted in physical locations, on websites, and sent with significant documents

§ 92.11 – Notice of availability of language assistance services and auxiliary aids and services

¹³ 87 Fed. Reg. 47850.

We support HHS's proposal to require notice of the availability of auxiliary aids and services for people with disabilities in health programs and activities. People with disabilities have improved access to health services when they are able to access appropriate auxiliary aids and services. Notice that clearly explains the breadth of Section 1557 rights, and provides information on how to practically access those protections, including contact information for the entity's Section 1557 coordinator, is particularly important for people with disabilities.

Access to accessible, nondiscriminatory care is further complicated by providers' lack of knowledge of disability-related responsibilities under nondiscrimination laws. For example, a recent study found that more than a third of U.S. physicians do not know their legal requirements under the ADA, and more than 70% did not know they share responsibility with patients for determining reasonable accommodations to ensure access to care, and 20% incorrectly identified who pays for those accommodations.¹⁴ Thus, it is critical that people with disabilities receive notice of their rights to auxiliary aids and services and, relatedly, for covered entities to develop procedures to ensure these notices are brought to the attention of people who have disabilities that can interfere with typical ways of reading and understanding the content of the notice. People with disabilities should be notified of their right to request effective communication and auxiliary aids and services, and detailed information about disability function and accommodation needs should be recorded in electronic health records. Including such information in electronic health records would decrease the burden of asking repeatedly for the same accommodations and provide information readily to providers about the needs of individuals they are serving.

While we support the notice requirements on auxiliary aids and services in § 92.11, we ask that the following recommendations be addressed to ensure people have meaningful access to communication services:

- Covered entities must ask members/beneficiaries whether they have communication disabilities and record their needed auxiliary aid or service in the electronic health record so that they can consistently receive effective communication from the covered entity.
- HHS should clarify that if an individual requests that all written communications be rendered in alternative formats or in LEP languages, then all future communications, including but not limited to the finite list of significant communications in subsection § 92.11(c)(5), should be provided in the requested

¹⁴ Lisa I. Iezzoni et al., *U.S. Physicians' Knowledge About the Americans with Disabilities Act and Accommodations of Patients with Disability*, Health Affs. (Jan. 2022), <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.01136>.

format or language.

- HHS should work on developing template notices in plain language formats that will make information accessible to people with intellectual and developmental disabilities.

Request for Information re: Data Collection

We appreciate HHS' attention to this important issue of data collection. People with disabilities are among the population groups that experience significant health disparities. They engage in preventive care at lower rates than recommended and report unmet health care needs.¹⁵ They delay or go without recommended care for a variety of reasons including disability related access barriers, such as provider inaccessibility, lack of accessible medical diagnostic equipment, and lack of necessary accommodations in health care settings.¹⁶ Health and health care disparities are compounded when disability intersects with race, ethnicity, gender identity, and age. The prevalence of disability increases with age and is especially high where age intersects with multiple marginalized identities, reflecting other systemic and historic barriers to health care experienced by these groups. Preliminary research suggests that there is less spending per capita on people of color with disabilities, but additional research is needed to determine why and how to remedy these systemic issues.¹⁷ We believe that comprehensive and stratified data collection on HCBS would be invaluable and we recommend that HHS adopt a demographic data collection requirement and establish demographic data collection as a function of civil rights monitoring.

We also urge HHS to focus on disability in data collection both in this final rule and overall civil and health care work. People with disabilities often get disregarded and overlooked in data collection and despite disabled people being the most impacted by health care, they are seldom the focus of efforts aimed at reducing health disparities. For example, although disability status is considered by the National Institute of Minority Health and Health Disparities to be a "fundamental characteristic" that may interact with health disparity populations, the disability community on its own is not named as a health disparity population, even though they are the largest minority group in the nation

¹⁵ Centers for Disease Control and Prevention, *Disability Impacts All of Us* (2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.

¹⁶ STAT News, *Many doctors are still befuddled by accommodating people with disability* (2022), <https://www.statnews.com/2022/01/13/doctors-confused-accommodations-people-disability/>;
Disability and Health Journal, Catherine Leigh Graham and Joshua R Mann, *Accessibility of primary care physician practice sites in South Carolina for people with disabilities* (2008) <https://pubmed.ncbi.nlm.nih.gov/21122731/>.

¹⁷ Alta California Regional Center, ACRC Purchase of Service Expenditure and Demographic Data, Fiscal Year 2020/2021, https://www.altaregional.org/sites/main/files/file-attachments/fy_20-21_pos_exp_data_-_english_1.pdf?1646342483.

with one in every 4 adults having some type of disability.¹⁸ This must change to provide proper treatment fairly and equitably to people with disabilities, especially disabled people of color and disabled individuals from other underrepresented communities.

Furthermore, a significant amount of disability research and data collection is based on the disability status question, where a disabled individual must identify as having one of the following: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, or independent living difficulty. We believe that this question to determine the nature of one's disability is very limiting and must be expanded in order to not miss out on a subset of the disability community. There are many individuals whose disabilities cannot be described simply as one of these six labels, especially those with certain learning and intellectual disabilities, whose health care needs may be deprioritized because they are being missed in the data collection. Expanding the question by adding another category and by giving individuals the ability to disclose and describe their own disability identity will enable providers, health care entities, and anyone doing civil rights work to truly capture the diversity of the disability community. The first step to making sure the health needs of the disability community are met is to ensure that we are properly and accurately recognized when it comes to research efforts and resource allocation.

Another way for HHS to better systematically collect data on disability status in health care is to address the long standing need for standard disability data elements in electronic health records (EHRs). The electronic health record (EHR) is an essential tool in linking demographic and clinical data within and across health care systems and public health databases. Data collected within the EHR is crucial to understanding and addressing inequities that negatively impact health and health care outcomes of marginalized communities, including people with disabilities. The lack of standardized collection of patients' disability status within EHRs has obscured our understanding of health inequities for people with disabilities and inhibited solutions.

Moreover, federal law requires structural accessibility, effective communication, and reasonable modifications of policies and procedures, so people with disabilities have equally effective access to health care services. However, covered entities will never provide or consistently offer effective communication and reasonable modifications unless they know what patients need and can plan to meet those needs. Maintaining granular information about functional limitations in the EHR is the first step in identifying needed accommodations.

¹⁸ National Institutes of Health, Minority Health and Health Disparities Strategic Plan 2021-2025, <https://www.nimhd.nih.gov/docs/nimhd-strategic-plan-2021-2025.pdf>. See also *supra* note 15.

We recommend that at a minimum, the American Community Survey (ACS) functional limitation questions be used to collect patients' disability status. This approach promotes interoperability between the EHR and other US population surveys. This uniform approach allows disability data to be linked across health care settings and aggregated into public health information systems. While these disability questions are not comprehensive of all disabilities (as discussed above), the current evidence and use in national surveys make using the ACS questions the best place to start. However, these efforts to include disability questions in EHR should be followed by support to improve and identify questions and methods that more comprehensively identify people across the range of disability types. For instance, the United Nations' Washington Group on Disability Statistics questions have also been incorporated into national surveys. The Washington Group set of six questions has briefer wording and notably includes a question on speech and language disabilities, collectively referred to as communication disabilities. The inclusion of a communication disability question will be significant because 10 percent of the US adult population has a communication disability. Additionally, the most frequent ADA complaint in health care is the lack of effective communication for patients with communication-related disabilities.

SUBPART B

§ 92.101 Discrimination Prohibited

Proposed § 92.101(b)(1) applies regulations implementing Section 504 of the Rehabilitation Act to health programs or activities that receive federal financial assistance, State Exchanges, and Federally-facilitated Exchanges. Specifically, the proposed section incorporates by reference 45 C.F.R. Parts 84 and 85, regulations pertaining to program accessibility.

We support HHS' general goal of explicitly incorporating into paragraph (b) the specific prohibitions on discrimination found in each of the civil rights laws on which Section 1557 is grounded. We think this approach is prudent, given that some health care entities may not be readily familiar with the specific regulatory standards and obligations that apply to them under Section 504 and the Americans with Disabilities Act ("ADA").

However, care must be taken not to incorporate standards that do not fully reflect the requirements of Section 1557 or the changes the ACA brought to nondiscrimination in health care. We are specifically concerned that the incorporation of 45 C.F.R. §§ 84.22, 85.42, Section 504's regulations pertaining to the accessibility of existing facilities, will create inconsistencies regarding the obligations of covered entities. Additionally, we object to the incorporation of § 84.23(c), which applies an outdated standard (the Uniform Federal Accessibility Standards) to new constructions.

A. Sections 84.22 and 85.42

First, we are concerned with the incorporation by reference of §§ 84.22 and 85.42 to health care entities covered under Section 1557. These regulations incorporate a concept of “program accessibility” that was developed in the 1990s for existing government facilities. The concept allowed government programs to assess the physical accessibility of a program or activity “in its entirety,”¹⁹ in recognition that many federal and federally-funded operations took place in older buildings and locations that would be difficult to modify in every instance. The regulations also stated that the standard “does not require a recipient to make each of its existing facilities or every part of a facility” accessible to and useable by people with disabilities.²⁰

While this concept of “overall accessibility” may have been appropriate to apply to federal and federally-funded programs 40 years ago, it is not appropriate to apply to the broad array of health programs and activities covered by Section 1557. In particular, we are concerned about the application of this standard to health insurers. The application of the “in its entirety” standard to these programs could theoretically allow an insurer to claim that their network is “accessible,” even if there is discrimination in individual provider settings.

To be clear, health providers are already independently subject to the accessibility requirements of Title III of the ADA and/or Section 504, as well as additional provisions of Section 1557 (including proposed § 92.203, related to accessible buildings and facilities). Additionally, the general prohibition on discrimination at proposed § 92.101(a) should take primacy over the specific forms of discrimination at paragraph (b)(1). However, the incorporation of §§ 84.22 and 85.42 creates inconsistency, seeming to allow discrimination within larger “programs,” even when their subparts are independently subject to nondiscrimination requirements.

To address this inconsistency, we recommend that HHS review the incorporation of §§ 84.22 and 85.42 and, if necessary, clarify that the “subparts” of programs must also comply with Section 1557’s nondiscrimination prohibitions.

B. Section 84.23(c)

Second, we object to the wholesale incorporation of Part 84 because it would incorporate § 84.23(c), a provision that allows facilities to only conform with the Uniform Federal Accessibility Standards (“UFAS”), instead of the more recent 1991 Americans with Disabilities Act Standards for Accessible Design (“1991 Standards”) or 2010 ADA

¹⁹ 45 C.F.R. §§ 84.22(a), 85.42(a).

²⁰ *Id.* §§ 84.22(a), 85.42(a)(1).

Standards for Accessible Design (“2010 Standards”).

UFAS is outdated and functionally deficient for people with disabilities, as HHS itself recognized when it explicitly declined to incorporate § 84.23(c) into the original Section 1557 regulations.²¹ In particular, UFAS permits facilities to maintain barriers that exclude people with disabilities that impact their mobility or strength. For example, it allows hazardous ramp slopes, permits inaccessible showers, and gives little consideration to the unique accessibility needs in medical care facilities. It is inappropriate to incorporate this nearly 40-year-old standard into the Section 1557 regulations.

Additionally, incorporating § 84.23(c) creates an inconsistency within the Section 1557 regulations. Proposed § 92.203(b)–(c) retains a thoughtful standard for the architectural accessibility of covered facilities, requiring constructions and alterations on or after July 18, 2016 to comply with the 2010 Standards and those before that date to comply with the 1991 Standards (with more lenient standards for newly-covered entities). The incorporation of § 84.23(c)—while certainly not absolving a covered entity of its obligation to comply with proposed § 92.203—creates confusion. We recommend omitting this provision from the incorporated regulations at proposed § 92.101(b)(1)(i).

RECOMMENDATION: Add the following language to § 92.101(b)(1)(i):

(i) A recipient and State Exchange must comply with the specific prohibitions on discrimination in the Department’s implementing regulations for Title VI, Section 504, Title IX, and the Age Act, found at parts 80, 84 (**except for § 84.23(c)**), 86 (subparts C and D), and 91 (subpart B) of this subchapter, respectively. Where this paragraph cross-references regulatory provisions that use the term “recipient,” the term “recipient or State Exchange” shall apply in its place. Where this paragraph cross-references regulatory provisions that use the term “student,” “employee,” or “applicant,” these terms shall be replaced with “individual.”

SUBPART C

§ 92.201 - Meaningful access for limited English proficient individuals

Translation encompasses more than simply switching from one language to another. Whether or not translation is accurate can be critical to patients. Research shows that

²¹ “We do not propose adopting the program accessibility provision at § 84.23(c), addressing conformance with the Uniform Federal Accessibility Standards for the construction and alteration of facilities, because these standards are outdated.” HHS Nondiscrimination in Health Programs and Activities; Notice of Proposed Rulemaking, 80 Fed. Reg. 54172, 54181 (Sept. 8, 2015).

limited proficiency in English is highly correlated to unmet needs in the health care setting. With respect to autism diagnoses, one study showed:

Latinx families with limited English proficiency are more likely than white families to experience hostility toward their language and report distrust in clinical professionals and the health care system, hence serving as additional barriers to receiving diagnosis which is crucially needed in order to obtain services.²²

Latinx children whose families' preferred language is Spanish experienced difficulty being assessed with autism by predominantly English-speaking and white clinical professionals, and few received autism screenings in Spanish, demonstrating that the process of assessment is not culturally and linguistically well-equipped to be used in Latinx communities.²³ Consequently, the stated rule should ensure that individuals who prefer a non-English language and other individuals with multiple disabilities facing structural barriers are guaranteed access to the appropriate communication tools necessary to make effective communication possible (including sign language in a language they are familiar with, not simply American Sign Language as default).

Regarding the use of machine translation in health programs and activities, we adamantly agree that such translation should only be acceptable in exigent circumstances. Furthermore, when machine translation is used, the individual should be notified that the machine technology was provided in lieu of a human translator due to an exigent circumstance, thus the translation may not be entirely accurate. Also, the translated printed materials of all covered entities should always be reviewed by a qualified human translator, not just documents that are "critical" to the individuals' rights, benefits or meaningful access. This is critical to ensuring that accuracy is prioritized.

§ 92.202 - Effective communication for individuals with disabilities

We support the provisions in this section regarding effective communication for people with disabilities. Effective communication is critical to ensuring that people with disabilities have access to quality health care. Research has shown that people with disabilities that impact communication have a more difficult time accessing health care, often delaying or foregoing care altogether.²⁴ For example, studies show that people

²² Katharine E. Zuckerman et al., *Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families*, *Pediatrics*, 139 (May 2017).

²³ Katharine E. Zuckerman et al., *Pediatrician identification of Latino children at risk for autism spectrum disorder*. *Pediatrics* (Sept. 2013) (few Autism screenings in Spanish); Katharine E. Zuckerman et al. *To reduce the average age of autism diagnosis, screen preschoolers in primary care*. *Autism* (Feb. 2021).

²⁴ Michelle L. Stransky et al., *Adults with Communication Disabilities Experience Poorer Health and Healthcare Outcomes Compared to People without Communication Disabilities*, 33 *J. Gen. Internal Med.* 147 (2018), <https://link.springer.com/article/10.1007/s11606-018-4625-1>.

who are deaf and hard of hearing routinely experience communication barriers in health care settings and are frequently dissatisfied by patient-provider communication.²⁵ Conversely, access to ASL-fluent doctors for deaf individuals who prefer that mode of communication has been linked with significantly higher utilization rates of preventative care, including cholesterol screens, colonoscopy, and influenza vaccines.²⁶ Additionally, lack of accurate and effective communication can lead to misdiagnosis, erroneous treatment, and ultimately a negative impact on the health or life of the patient.²⁷

We also note that since the HEW 504 rules were first issued, the basic duty to assure effective communication has revolved around the requirement to provide auxiliary aids and services. The provision of auxiliary aids and services is a necessary but far from a sufficient tool for avoiding and remedying effective communication discrimination. This is particularly true with regard to the estimated four to five million children, youth, working-age people, and older adults who cannot rely on natural speech to effectively communicate with most others.²⁸ Instead, such individuals require, but all too frequently lack meaningful, effective access to the robust language-based Augmentative and Alternative Communication (AAC) they need to express themselves and be understood. A major cause and effect of this is that they are subjected to age-old unwarranted and disproven assumptions stereotypes that brand them as categorically being less intelligent; being unable to use or even devoid of language; and, having less of a human need, ability, or right to effectively communicate.

Indeed, the very fact that someone requires robust language-based AAC – rather than spoken words to effectively communicate – is often used to assume they are incapable of “effective communication.” Unfortunately, doctors and other health professionals are not immune from harboring and acting on such biases, which has led to the failure to obtain informed consent, lower quality of care, poor health outcomes, and the alleged preventable deaths of individuals with significant expressive disabilities.²⁹ All of this is

²⁵ Steven Barnett et al., *Deaf Sign Language Users, Health Inequities, and Public Health: Opportunity for Social Justice*, 8 Preventing Chronic Disease A45 (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3073438/>.

²⁶ Michael M. McKee et al., *Impact of Communication on Preventive Services Among Deaf American Sign Language Users*, 41 Am. J. Preventive Med. 75 (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3117257/>.

²⁷ See, e.g., Silvia Yee et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, Nat'l Acads. Sci. Eng'g. & Med. 43–44 (2017), <https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf> (summarizing and analyzing the abundance of research on this point).

²⁸ David R. Beukelman & Janice C. Light, *Augmentative and alternative communication: Supporting children and adults with complex communication needs*. (5th ed. 2020).

²⁹ Joseph Shapiro, NPR “As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?” (Dec. 14, 2020), <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc>; Lisa I. Iezzoni et al., *U.S. Physicians’*

due to the continued refusal of health care professionals and systems to “do no harm” by meeting their legal obligations to effectively communicate with all and not just some patients with disabilities.

We are extremely appreciative that HHS has taken repeated actions throughout the pandemic to prevent and remedy this form of insidious discrimination. We, therefore, strongly urge HHS to incorporate the following HHS guidance directly into the final regulations as well as all its subsequent guidance, technical assistance, and enforcement activities: [Non Discrimination in Standards of Care -- March 28, 2020](#) ; and, [The Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19-- June 9, 2020](#).

Incorporating the major tenets of these guidance documents into the rules and related assumptions will send a clear and long overdue message to health care professionals and facilities across the U.S.: Refusing to effectively communicate with significant expressive disabilities or other disabilities based on ableism or other multiply marginalizing is bad medicine and violates several federal civil rights laws. Along similar lines, we believe it is critical that HHS stress in public communications and in regulations that health care professionals and facilities have an obligation to ensure that effective communication is available to Black, Indigenous, non-English-using, and People of Color who are more likely to acquire significant expressive disabilities and other disabilities and endure multiple forms of prejudice and discrimination.³⁰ HHS should also:

- Require covered entities to ensure, in a comprehensive and seamless manner, the effective communication rights of non-English-using people with significant expressive disabilities and other disabilities receive the comprehensive and well-coordinated language access and effective communication assistance they require.
- As noted above, ensure that technologies like machine translation are used with caution in order to assure accuracy in translation essential for safe, high-quality,

Knowledge About the Americans with Disabilities Act and Accommodations of Patients with Disability, Health Affs. (Jan. 2022), <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.01136>.

³⁰ Kulkarni and Palmer, *Culturally and Linguistically Diverse Student and Family Perspectives on Using Augmentative and Alternative Communication Devices*, American Educational Research Association Annual Meeting (AERA) (2017), <https://works.bepress.com/saili-kulkarni/15/>; Rhonda Davis, *Reflections of nine participants regarding their experiences of being African American and using augmentative and alternative communication across their lifespan at Home, School, Vocation, and Community* (Dec. 2005) (unpublished Ph.D. dissertation, Pennsylvania State University), https://etda.libraries.psu.edu/files/final_submissions/5216; Charles Ellis, *Young African American adults with aphasia: A case series*. 14 J. of the Nat'l Black Ass'n for SpeechLanguage and Hearing Journal 33 (2019).

and equitable care. This is critical for the health and well-being for individuals with any degree of atypical speech, are non-English speaking, or who use a speech generating device.

- As noted below in comments to § 92.207, we encourage HHS to take concerted steps to ensure the effective communication rights of individuals with significant disabilities and other disabilities that recognize and affirm the fact that effective communication is integral to achieving the central purpose of Section 504, the ADA, and Section 1557: Integration into the American community.

§ 92.203 - Accessibility for buildings and facilities

A. General Standard

CCD supports HHS's proposal to add a general provision to § 92.203 (proposed paragraph (a)), echoing the language of the Section 504 regulations and broadly establishing that no qualified individual with a disability shall, because a covered entity's facilities are inaccessible to or unusable by individuals with disabilities, be denied the benefits of, be excluded from participation in, or otherwise be subjected to discrimination under any health program or activity to which this part applies.

With this addition, we appreciate HHS's recognition that facility accessibility for people with disabilities goes beyond the architectural design and physical barriers that may be contained within a health care facility. Accessibility is needed by people with all sorts of disabilities, not just people with physical disabilities. It permeates every aspect of a facility—it is not just whether an individual can make it to and through the door, it is whether they can meaningfully access all health care services the facility or provider offers. Are there accessible tables, weight scales, and diagnostic equipment for people with mobility disabilities? Is the environment safe and accessible for individuals with sensory sensitivities? Are staff in the facility properly trained to accommodate and adapt to the needs of individuals with communication or mental health disabilities?

Proposed § 92.203(a) clarifies the protections that people with disabilities are guaranteed under Section 1557, and it more closely aligns with the requirements of Section 504 and the ADA. We agree that HHS should codify this provision. Further, we recommend that HHS add a provision to § 92.203 making clear that compliance with the specific architectural design requirements at proposed § 92.203(b)–(c) does not, alone, satisfy the general requirement of proposed paragraph (a). This addition is particularly important in light of HHS's consideration of adding medical diagnostic equipment ("MDE") standards to the Section 1557 regulations (discussed further below). Facility accessibility is broader than architecture, and it is important to codify this concept. For consistency, the language could closely track the text at proposed §§ 92.101(b)(2) and

92.207(d).

RECOMMENDATION: Add the following language to § 92.203:

(d) The enumeration of specific facility design standards in paragraphs (b) and (c) of this section does not limit the general applicability of the nondiscrimination prohibition in paragraph (a) of this section.

B. Architectural Standards

CCD supports HHS's proposal to retain the existing provisions of § 92.203 (proposed paragraphs (b) and (c)), regarding the architectural standards for a covered entity's buildings and facilities. We agree that the 2010 Standards and, in limited circumstances, the 1991 Standards are the appropriate standards for facilities where health programs or activities are conducted.

We emphasize the importance of a continued push towards universal compliance with the 2010 Standards. As the few health care entities who are not already subject to the more recent standards alter or update their facilities, it is critical that HHS provide oversight to ensure that such facilities come into compliance with the 2010 Standards. Health care consumers with disabilities are promised greater accessibility under the 2010 Standards, as compared to the 1991 Standards. For example, the newer standards have specific provisions that apply to "medical care facilities," which require facilities to offer accessible patient rooms in every medical specialty unit.³¹ Such contextual specificity makes the 2010 Standards more appropriate for adoption by Section 1557 entities and more beneficial to individuals with disabilities.

The uniform application of the 2010 Standards will also enable greater consistency among implementing agencies, given the overlapping jurisdiction of HHS's Office for Civil Rights with the U.S. Department of Justice (the latter of which enforces the 2010 Standards as applied to ADA Title II entities). Complainants with disabilities should not have the added burden of trying to figure out the date on which a health care facility's construction or alteration began in order to then determine which administrative forum is appropriate to enforce their rights. We appreciate HHS's ongoing commitment to simplifying this process and ensuring that all health care facilities are physically accessible for people with disabilities.

C. Medical Diagnostic Equipment Standards

³¹ 28 C.F.R. § 35.151(h).

CCD recommends that HHS reference and incorporate the 2017 Standards for Accessible Medical Diagnostic Equipment (“MDE Standards”), 36 C.F.R. pt. 1195, into § 92.203. The MDE Standards, which implement Section 510 of the Rehabilitation Act, set forth minimal technical criteria for the accessibility of MDE in facilities where health programs or activities are conducted.³² Incorporating these standards into Section 1557 is a necessary step towards improving access to health care services for individuals with disabilities.

As HHS has identified, people with disabilities continue to “fare worse on a broad range of health indicators than the general population.”³³ For example, adults with disabilities are 58 percent more likely to experience obesity, three times more likely to be diagnosed with diabetes, and nearly four times more likely to have early-onset cardiovascular disease.³⁴ They are also more likely to have high blood pressure and experience symptoms of psychological distress.³⁵

These disparities in health outcomes are closely linked to a lack of timely access to quality primary and specialty health care services. Both children with disabilities and adults with disabilities are more than twice as likely as their nondisabled counterparts to report unmet health care needs.³⁶ Further, adults with disabilities are significantly less likely to receive preventative and diagnostic health services, including primary care appointments, cervical cancer screenings, and mammograms.³⁷

Disparities in access to care can be traced, in part, back to a widespread lack of accessible MDE in provider facilities. Examination tables, weight scales, and imaging equipment are critical to health maintenance and diagnosis, yet they are often not

³² 29 U.S.C. § 794f; 36 C.F.R. pt. 1195.

³³ 87 Fed. Reg. 47836.

³⁴ Yee et al., *supra* note 25, at 32.; *see also, e.g.*, Valerie L. Forman-Hoffman et al., *Disability Status, Mortality, and Leading Causes of Death in the United States Community Population*, 53 *Med. Care* 346 (Apr. 2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5302214/>; Elham Mahmoudi & Michelle Meade, *Disparities in Access to Health Care Among Adults with Physical Disabilities: Analysis of a Representative National Sample for a Ten-Year Period*, 8 *Disability Health J.* 182 (Apr. 2015), <https://pubmed.ncbi.nlm.nih.gov/25263459/>.

³⁵ Lisa Iezzoni et al., *Trends in U.S. Adult Chronic Disability Rates Over Time*, 7 *Disability & Health J.* 4, 402–12 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4167341/>.

³⁶ Yee et al., *supra* note 25, at 31.

³⁷ *See, e.g., id.*; Brian S. Armour et al., *State-Level Differences in Breast and Cervical Cancer Screening by Disability Status: United States*, 19 *Womens Health Issues*, no. 6, at 406-414 (Dec. 2009), <https://pubmed.ncbi.nlm.nih.gov/19879454/>; H. Stephen Kaye, *Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act*, 109 *Am. J. Pub. Health* 7, 1015–21 (July 2019), <https://pubmed.ncbi.nlm.nih.gov/31095413/>; Michael Stillman et al., *Healthcare Utilization and Associated Barriers Experienced by Wheelchair Users: A Pilot Study*, 10 *Disability & Health J.* 4, 502–08 (Oct. 2017), <https://pubmed.ncbi.nlm.nih.gov/28245968/>.

accessible for people with mobility disabilities.³⁸ For example, a recent study of nearly 4,000 primary care offices in California found that only 19 percent of facilities had accessible examination tables, and only 11 percent of facilities had accessible scales.³⁹ Even when provider facilities have accessible MDE, staff is often not properly trained in how to use the equipment, leading to underutilization.⁴⁰

The lack of access to accessible MDE compromises the quality of care that people with disabilities receive, and it can lead to missed or delayed diagnoses of potentially life-threatening conditions.⁴¹ Further, the lack of accessible MDE in provider facilities has been shown to negatively impact the mental health of people with disabilities and cause many individuals to forgo needed preventative care.⁴²

In order to help alleviate the widespread lack of access to MDE, and the health disparities that result from it, HHS should issue regulations requiring Section 1557 covered entities to comply with the MDE Standards at 36 C.F.R. pt. 1195. Although Section 504, Titles II and III of the ADA, and Section 1557 prohibit discrimination on the basis of disability in health care settings, systemic improvements in the accessibility of MDE have failed to materialize. Similar to the time period prior to the adoption of architectural design standards, covered entities have resorted to case-by-case solutions for MDE access and failed to incorporate appropriate systemic solutions.⁴³ Now, we have specific standards in hand. The U.S. Access Board developed comprehensive, vetted standards to combat widespread MDE access barriers.⁴⁴ While we recognize that HHS must still develop scoping requirements for these standards, and that this process will take time, we encourage the Department to take the first step towards greater accessibility by adopting the MDE Standards while the Section 1557 regulations are otherwise being amended.

³⁸ Nat'l Council on Disability, *Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* 16 (May 20, 2021), <https://ncd.gov/publications/2021/enforceable-accessible-medical-equipment-standards> (hereinafter "NCD Report").

³⁹ Nancy Mudrick et al., *Presence of Accessible Equipment and Interior Elements in Primary Care Offices*, 3 *Health Equity* 1, 275–79 (June 2019) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6585465/>.

⁴⁰ NCD Report, *supra* note 36, at 16.

⁴¹ *Id.* at 16–20.

⁴² See, e.g., Amanda Reichard et al., *Prevalence and Reasons for Delaying and Foregoing Necessary Care by the Presence and Type of Disability Among Working-Age Adults*, 10 *Disability & Health J.* 1, 39–47 (2017) <https://pubmed.ncbi.nlm.nih.gov/27771217/>; Carrie Basas, *Advocacy Fatigue: Self-Care, Protest, and Educational Equity*, 32 *Windsor Yearbook of Access to Justice* 2, 37 (2015), <https://wyaj.uwindsor.ca/index.php/wyaj/article/view/4681>.

⁴³ NCD Report, *supra* note 36, at 24–26.

⁴⁴ 29 U.S.C. § 794f; 36 C.F.R. pt. 1195.

To truly ensure nondiscrimination, equipment must be made accessible across disability communities. We urge HHS to consider *additional* medical equipment accessibility standards to account for the needs of individuals with visual, sensory, and other functional limitations; and account for settings outside provider offices or hospitals. We urge HHS to ensure that the Section 1557 regulations (as well as other similar regulations currently under review) consider the full range of medical equipment that must be made accessible, including at-home diagnostic tools, telehealth equipment, and other equipment used in the health care setting, such as electronic forms, check-in and billing kiosks, and other frequently inaccessible tools that patients encounter. Of course, these latter categories may overlap with the requirements to provide accessible information and communication technology, and we refer to our comments elsewhere in this letter regarding such equipment.

RECOMMENDATION: Add the following language to § 92.203:

Medical Diagnostic Equipment Standards.

(1) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment shall comply with 36 CFR part 1195.

(2) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

Additionally, HHS requests comment on whether the lack of access to MDE would constitute a discriminatory benefit design or network inadequacy. We recommend that it be considered a matter for both.

Benefit design requirements, as articulated in proposed § 92.207(b)(2), require health insurers to proactively consider accessibility as an integral component of what constitutes a health care benefit.⁴⁵ For example, if a health plan covers primary care office visits, but providers do not have examination tables that are accessible to the patient (thus inhibiting or preventing a full examination), then meaningful access to that

⁴⁵ See also, e.g., *Schmitt v. Kaiser Found. Health Plan of Wash.*, 965 F.3d 945, 949 (9th Cir. 2020) (affirming that Section 1557 prohibits discriminatory benefit designs); *Doe v. CVS Pharmacy, Inc.*, 982 F.3d 1204, 1211–12 (9th Cir. 2020) (affirming that a beneficiary must have “meaningful access” to a benefit).

benefit has been denied. In other words, if access to a benefit depends on access to MDE, then lack of access to that MDE constitutes a discriminatory benefit design.

Likewise, if a health insurer or managed care entity fails to offer a provider network that consists of an adequate amount of primary care and specialty providers with accessible MDE, it could violate Federal and State network adequacy requirements. Equipment accessibility should be considered in conjunction with other important components of network adequacy, such as time and distance standards and provider-member ratios.

Ultimately, lack of access to MDE relates to multiple aspects Section 1557's nondiscrimination provisions. It is not only a straightforward violation of proposed § 92.203(a), concerning facility accessibility, but it also creates a ripple effect—impacting a covered entity's benefit design and network adequacy. To resolve this intractable problem, and assist covered entities in coming into compliance with Section 1557, clear standards should be established. HHS should incorporate the above-suggested language in § 92.203.

§ 92.204 - Accessibility of information and communication technology for individuals with disabilities

HHS seeks comment on proposals relating to accessibility of information and communication technology (ICT) for people with disabilities. These provisions, which are substantially the same as prior iterations of the Section 1557 regulations, require covered entities to ensure that “their health programs and activities provided through ICT are accessible to individuals with disabilities,” unless undue burden or a fundamental alteration would result. In such cases, covered entities are required to take any other action that would enable, to the maximum extent possible, individuals with disabilities to receive the benefits or services of the program or activity (i.e., make reasonable accommodations).

HHS also proposes to apply the existing requirements applicable to recipients' and State Exchange websites to apply to mobile applications as well. The existing regulation, as well as the proposed rule, do *not* currently require covered entities to comply with specific accessibility standards, an omission that applies to other areas of law and regulation requiring accessibility of ICT (such as the requirements of Titles II and III of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act). HHS does note that “[m]any covered entities are currently relying on Section 508 standards promulgated by the Access Board or Web Content Accessibility Guidelines (WCAG)... to ensure that their ICT is accessible.”

HHS now seeks comment on whether the Section 1557 rule should include a requirement to comply with specific accessibility standards, as well as whether to adopt a safe harbor for entities in compliance with such standards and whether to require compliance with “the most recent edition of a published standard.”

CCD has time and time again emphasized the importance of ensuring web and ICT accessibility, especially with regards to the provision of health programs and activities. Within the scope of the Section 1557 regulations, and in other areas (such as the soon-to-be updated Section 504 regulations), HHS should ensure that covered entities ***procure, design, maintain, and use websites and other ICT that are accessible to and usable by the widest range of individuals with disabilities possible.*** Despite the aforementioned requirements to do, many covered entities fail to offer accessible health care ICT, resulting in significant harm to individuals with disabilities who are unable to utilize the health care services to which they are entitled.

The inaccessibility of websites, online systems, mobile applications, and other forms of ICT presents a clear, growing, and present danger to the welfare of people with disabilities across all sectors, but especially in the health care field. Especially given the expanded use of telehealth and reliance on remote ICT services during the COVID-19 pandemic, the impact of inaccessible health care ICT is becoming more and more burdensome on individuals with disabilities, severely impacting access to care. Without clear standards, entities providing ICT frequently fail to provide accessible systems, whether by design, carelessness, or a lack of understanding of what is required to be in compliance with existing requirements.

We urge HHS to include specific, clear, and enforceable ICT accessibility and usability standards that align with current requirements under Section 508 of the Rehabilitation Act, including the incorporation by reference of the internationally accepted Web Content Accessibility Guidelines (WCAG) 2.1 Levels A and AA. As the proposed rule references, these standards, developed by the international standards body the Worldwide Web Consortium (W3C), are regularly evolving through an expert stakeholder development and consensus process. We encourage OCR to develop regulatory language clarifying that compliance should relate to the currently accepted version of WCAG as well as successor standards as they are finalized and published. Further, we encourage OCR to ensure that the regulations continue to make clear that ICT encompasses not only websites, but mobile applications, online systems, and other forms of ICT – all of which should be made accessible to individuals with disabilities. Lastly, if and when OCR finalizes these regulations, we urge OCR to establish and communicate to covered entities clear consequences for failures to comply with and implement these accessibility requirements.

Last, in response to HHS’s request for comment, we have concerns about using a set of published standards like WCAG as a safe haven for covered entities for the purposes of this section. While WCAG provides an excellent baseline for accessibility of web content, the standards may not encompass all forms of ICT included in HHS’s definition in 45 C.F.R. § 92.4, such as information kiosks, transaction machines, or telehealth interfaces, that are not centered on web content. Accessibility depends on making each step and component of the use of technology as accessible as possible. Creating a safe harbor based on content-focused WCAG standard might lead to oversight of important contextual details that are key to successful accessible communications.

Moreover, WCAG’s standards note that:

even content that conforms at the highest level (AAA) will not be accessible to individuals with all types, degrees, or combinations of disability, particularly in the cognitive language and learning areas.⁴⁶

While we support the proposal to require covered entities to comply with a specific set of accessibility standards, compliance is such standards is simply a baseline, and not necessarily evidence of compliance. Because Section 1557 protects accessibility at the individual level, covered entities still have an obligation under proposed § 92.204 to seek and provide reasonable accommodations for individuals for whom ICT that meets published standards remains inaccessible. Creating a safe harbor requiring only that ICT content meet a certain level of WCAG or § 508 standards may make it harder for such individuals to obtain needed individual accommodations.

§ 92.205 - Requirement to make reasonable modifications

As we commented in 2015 and 2019, we continue to believe that the language in § 92.205 conforms with other non-discrimination regulations and maintaining the exiting language makes these standards consistent with the ADA and other regulatory schemes. In 2015, we urged the Department to strengthen the section by adding language to clarify that modifications to add medically necessary care for individuals with disabilities, or eliminating exclusions of medically necessary services, are not considered fundamental alterations to the nature of the health program. We reiterate that suggestion here and also recommend that HHS provides examples of

⁴⁶ Worldwide Web Consortium (W3C), *Web Content Accessibility Guidelines (WCAG) 2.1* (June 5, 2018), <https://www.w3.org/TR/WCAG21/#background-on-wcag-2>.

programmatic modifications that may be needed by individuals with disabilities.⁴⁷ A few such examples could include:

- Coverage of anesthesia for dental services when necessary for an individual with a disability to access dental or other medical care; and
- Modification of wait times, office hours, and other business practices that may not be accessible for individuals with disabilities.

§ 92.207 - Nondiscrimination in health insurance coverage and other health-related coverage

We opposed the elimination of § 92.207 in our 2019 comments and strongly support its proposed reinstatement. The Department is correct that the rescission of this section created confusion and, as was extensively discussed in our 2019 comments, was contrary to the intent and purpose of the Affordable Care Act. For people with disabilities, the benefit design provisions have been crucial and the addition in this proposed regulation of an explicit provision detailing the integration mandate will ensure that this provision is correctly understood and interpreted. We also support the reinstatement of explicit inclusion of protections for transgender individuals. Some subpopulations within the disability community, such as Autistic individuals, have higher rates of transgender or gender-diverse identity and these protections are particularly important for those populations that face multiple forms of marginalization.⁴⁸

§ 92.207(b)(2) - Benefit Design

We agree with the Department that the 2020 rule resulted in less protection for people who need health care and who are protected by Section 1557 against discrimination. We strongly support the application of Section 1557 to health insurance coverage, especially health benefit designs.

By enacting the ACA, Congress intended to prohibit health insurance practices, including plan benefit designs, that discriminate on the basis of race, color, national origin, sex, age, or disability. The ACA improved the availability and quality of health insurance by prohibiting medical underwriting and requiring community-rating, guaranteed issue, and coverage of pre-existing protections. The ACA also sought to ensure adequate benefits by creating the ten Essential Health Benefits (EHB)

⁴⁷ Disability Education and Defense Fund, Nancy R. Mudrick and Silvia Yee, *Defining Programmatic Access to Healthcare for People with Disabilities* (2007), <https://dredf.org/public-policy/health-access-to-care-old/defining-programmatic-access-to-healthcare-for-people-with-disabilities/>.

⁴⁸ Varun Warriar, *Elevated Rates of Autism, Other Neurodevelopmental and Psychiatric Diagnoses, and Autistic Traits in Transgender and Gender-Diverse Individuals*, Nat Commun. (Aug 7, 2020), <https://pubmed.ncbi.nlm.nih.gov/32770077/>.

categories.

Section 1557 is key to achieving the goals of the ACA and enforcing its mandates, especially for people with disabilities and chronic conditions. People with disabilities frequently need multiple-high cost health care services. Without the prohibition on discriminatory marketing or benefit design, insurers will use marketing and benefit design to try to avoid enrolling people with disabilities in order to maximize their profits. For example, a health insurance plan may cover the fewest number of anti-seizure medications allowed and place them all in the highest cost-sharing tier in order to discourage enrollment of people with epilepsy and other conditions treated with anti-seizure medications. A plan might also arbitrarily limit rehabilitation services in order to reduce the services used by someone who acquires a disability during the plan year. Application of Section 1557 to marketing and benefit design is essential to protecting people with disabilities from insurers who will find roundabout ways to discourage their enrollment and undermine the protections for people with pre-existing conditions under the ACA.

The benefit design protections of the ACA ensure that necessary medication cannot be tiered away, that plans cannot refuse to cover certain medications or not follow treatment guidelines, cap coverage of habilitative or rehabilitative services or devices, and other crucial protections. But as we pointed out in both our 2015 and 2019 comments, guidance or other additional clarity on the exact parameters of this form of discrimination would be helpful, such as in the areas of habilitation and rehabilitation, age limits, access to disability-specific care such hearing aids, visit limits, unreasonable prior authorizations, step therapy, requiring patients to “try” lower tier drugs before accessing higher tier ones, and having overly narrow networks.

Additionally, health insurance companies routinely discriminate against individuals with mental illness—not only by failing to comply with the integration mandate, as noted below—but also via discriminatory benefit design. One example of mental health related discriminatory benefit design is provider network design. In the mental health context, insurers routinely make it more difficult for individuals to obtain mental health services than physical health services. For example, individuals are forced to go out of network much more often for outpatient mental health services than for similar outpatient physical health providers.⁴⁹ This lack of access to in network providers leads much higher out-of-pocket costs for mental health care than physical health care.⁵⁰ A major factor contributing to the lack of access to in-network providers is the low

⁴⁹ National Alliance on Mental Illness, *The Doctor is Out: Continuing Disparities in Access to Mental and Physical Health Care* (2017), <https://www.nami.org/Support-Education/Publications-Reports/Public-Policy-Reports/The-Doctor-is-Out/DoctorIsOut>

⁵⁰ *Id.*

reimbursement rate many insurers pay to mental health providers.⁵¹ Insurers must not design plans and networks and reimburse services in a manner that makes it more difficult to access mental health care than physical health care, nor screen out individuals who have significant mental health care needs.

§92.207(b)(6) - Integration Mandate

One area where we have consistently requested additional clarity from the Department is around the application of the provisions of Section 504 and the Americans with Disabilities Act known as the integration mandate. We are strongly supportive of the addition of explicit regulatory text addressing this issue. Section 1557 explicitly references Section 504, which has regulatory requirements to provide services and programs in the most integrated setting appropriate to the needs of individuals with disabilities and has consistently been interpreted as requiring those receiving federal financial assistance to not segregate individuals with disabilities from their communities.⁵² Importantly, Section 504 also prohibits covered entities from utilizing criteria or methods of administration that “have the purpose of or effect defeating or substantially impairing accomplishment of the objectives of the recipient’s program or activity” or otherwise discriminates against people with disabilities.⁵³ Therefore, covered entities under Section 1557 are prohibited from providing health programs and services in settings that are more segregated than are appropriate to the needs of people with disabilities, and from employing coverage policies, benefit design, coverage decisions,

⁵¹ Gov’t Acct. Office, *Mental Health Care: Consumers with Coverage Face Access Challenges, Testimony Before the Committee on Finance*, U.S. Senate (March 30, 2022), <https://www.gao.gov/assets/720/719824.pdf>

⁵² 45 C.F.R § 84.4(b)(2) (“aids, benefits, and services . . . [must afford equal opportunity] . . . in the most integrated setting appropriate to the person’s needs.”); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999); see, e.g., *Pashby v. Delia*, 709 F.3d 307, 321 (4th Cir. 2013) (both Section 504 and the ADA contain the same integration requirements and the claims may be considered together); *Am. Council of the Blind v. Paulson*, 525 F.3d 1256, 1266 (D.C. Cir. 2008); *Henrietta D. v. Bloomberg*, 331 F. 3d 261, 272 (2d Cir. 2003); see also *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003) (where the issue is the location of services provided -- institution versus community -- rather than whether services should be provided, *Olmstead* controls). Although the Court in *Olmstead* noted that Section 504 does not contain the same express recognition that isolation or segregation of persons with disabilities is form of segregation, the regulations make such a recognition and case law enforcing the community integration mandate have consistently found violations of 504 due to segregation of people with disabilities and not providing services in the most integrated setting appropriate to their needs. See, e.g., *Day v. D.C.*, 894 F. Supp. 2d 1, 4 (D.D.C. 2012) (noting the lack of express recognition but relying on the regulations); *Steimel v. Wernert*, 823 F.3d 902, 911 (7th Circ. 2016) (finding integration mandate violations because the Defendant’s service system design, planning, funding choices, and service implementation promoted or relied on segregation of people with disabilities); *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 462 (6th Cir. 2020) (policies limiting plaintiffs’ access to the community and activities violated the integration mandated).

⁵³ 45 C.F.R. 84.4(b)(4).

and other criteria and methods of administration that will do the same.

People with disabilities were historically segregated in institutional settings due to ablism and misconceptions about ability; this systemic discrimination continues today and is built into many of health care systems and processes.⁵⁴ This needless segregation of individuals with disabilities identified clearly in *Olmstead v. L.C.*, 527 U.S. 581 (1999), continues through the structure and processes of health care today, as discussed in our previous comments. The ACA dramatically shifted what discrimination in health care and health-related services looks like, especially for non-public health plans.⁵⁵ While Section 504 allowed various insurance policies that discriminated against people with disabilities, the ACA – and the incorporation of Section 504 in Section 1557 -- explicitly prohibited many of these same policies.⁵⁶

We are extremely glad that the HHS has provided an explicit mention in the regulatory text and extensive discussion in the proposed rule about the details of this discrimination. We strongly support the proposal's specific mention of "utilization management practices, provider reimbursement, contracting out to third party-contractors such as pharmacy benefit managers, and quality measurement and incentive systems" as areas where covered entities should pay careful attention. We also agree with HHS's examples of plans requiring prior authorization or step therapy or other utilization management when individuals are accessing a medication in the community, but not using these tools when individuals are institutions would count as discrimination.

We would expand on these examples in response to the HHS's question about scope and nature of this protection. One example relates to anti-seizure medications. Rescue medications administered to a person while they are actively having a seizure or series of seizures. For several decades, non-hospital-administered rescue medications were only available in a rectal gel route of administration. In 2020 and 2019 Food and Drug Administration (FDA) approved two new rescue therapies that use a nasal spray route of administration.

Unfortunately, state Medicaid programs continue to deny, or put into place step therapy

⁵⁴ National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives* (Sept. 29, 2003), <https://ncd.gov/publications/2003/aug192003>.

⁵⁵ See Amicus Brief of Nat'l Health L. Program et al. in *Doe v. CVS*, available at <https://healthlaw.org/resource/amicus-brief-from-national-health-law-program-in-cvs-v-doe/> (discussing history of disability discrimination in health coverage and how the ACA changed the landscape, but did so in a way that allows insurers to have nondiscriminatory limitations on coverage and services); *Schmitt v. Kaiser*, 965 F.3d 945, 954-59 (discussing how Section 504 may not have prohibited discriminatory benefit design, but the ACA and Section 1557 does).

⁵⁶ *Id.*

protocols, on these medications. Step therapy requires the individual to “fail” on the rectal gel before they can obtain coverage for the nasal spray. Due to the sensitive nature of rectal administration, covering only rectal gel has the effect of limiting the ability of people with epilepsy to fully participate in their communities. The alternative route of administration expands the places that people with epilepsy can have their medications administered and the people who are trusted to administer the drug. We urge the administration to investigate these exclusions or step therapy protocols for their potential impact on the isolation of people living with epilepsy.

We urge HHS to investigate aspects of health coverage that may result in more isolation and segregation of individuals with disabilities, including prescription drug formulary design and utilization management practices. For many individuals with disabilities, coverage and access to the right prescription medications is the difference between life in the community and isolation, segregation, and potential institutionalization.

Another example is when one is denied the opportunity, means, and right to effectively communicate, they are not perceived or treated as belonging to any community. They are instead subjected to what the Olmstead decision refers to as “unjustified isolation” and denied access to the rights and benefits of community living, including access to quality rather than substandard health care.

A further example is the prohibition on retroactive coverage of HCBS and the fact that HCBS will not be covered for any date preceding the date on which a Medicaid HCBS service plan is approved.⁵⁷ This is not the case for nursing facilities, where retroactivity is possible.

And as mentioned above, there are substantial barriers to mental health services. Many non-public insurance plans are far more likely to cover a hospitalization but offer limited home care, or they may cover residential treatment for mental health or substance use disorder, but do not offer intensive community-based mental health or substance use disorder services that serve as an alternative to institutionalization.⁵⁸

⁵⁷ Centers for Medicare & Medicaid Services, *Application for a § 1915(c) Home and Community-Based Waiver; Instructions, Technical Guide and Review Criteria*, at 52, 73 (Appendix B), 190 (Appendix D-1):

⁵⁸ See, e.g., Molly O’ Malley Watts et al., Kaiser Fam. Found., *Medicaid Home and Community-Based Services Enrollment and Spending* (Feb. 4, 2020) (Medicaid fills a gap by covering home and community-based services not typically available through private insurance or Medicare); MaryBeth Musumeci et al., Kaiser Fam. Found., *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey* (July 11, 2022), <https://www.kff.org/report-section/medicaid-financial-eligibility-in-pathways-based-on-old-age-or-disability-in-2022-findings-from-a-50-state-survey-issue-brief/> (identifying state Medicaid programs that provide buy-in coverage or supplementary coverage; coverage for children of families that may otherwise have health coverage, such as the Katie Beckett option or waiver programs, but who need community-based services); Tami L. Mark et al., *Insurance*

We note that we strongly disagree with the language in the preamble that a covered entity like a state Medicaid program would generally not be required to provide a new benefit because that would fundamentally alter the program.⁵⁹ This language, although it includes the qualifier of “generally”, is not entirely consistent with case law and could lead to arguments that would unjustly be relied upon by covered entities to limit access to non-discriminatory, integrated care.⁶⁰ We ask that HHS correct this language in the publishing of the final rule. Although a covered entity may be able to use a fundamental alteration defense to establish that creation of a new service would fundamentally alter their services or otherwise be unreasonable, they may sometimes be required to create a new service to avoid discrimination. For example, a covered entity that provides for services in an institutional setting may have to create those services in the community where they have not existed before, including creating coverage policies, provider networks, and other functionalities to ensure that people with disabilities are not forced to go to more segregated settings than are appropriate for their needs to receive the service. In one practical example, an insurer that only provides for residential treatment for certain SUD conditions and does not provide coverage of such services in community-based settings that are clinically appropriate may need to “create” a new benefit in that they have not offered that benefit in the community before, it may go under a different name with different clinical standards, etc. In addition, an entity may have to cover a service that it may want to term as “new” in order to not be discriminatory in coverage even though the service sought is within the existing services being provided.⁶¹

Network Adequacy

We appreciate the Department’s attention to network adequacy and how plan choices regarding provider networks may violate Section 1557. The Department is correct that

Financing Increased for Mental Health Conditions but Not for Substance Use Disorders, 1984-2014, 35 Health Affairs 958, 963 (2016), <https://perma.cc/DD66-XFQL> (discussing the costs to public insurance of private insurers’ failure to cover mental health and substance use disorder services).

⁵⁹ 87 Fed. Reg. 47873.

⁶⁰ See, e.g., *Townsend*, 328 F.3d at 516-521; *Hampe v. Hamos*, 917 F.Supp.2d 805 (N.D. Ill. 2013); *Lane v. Kitzhaber*, 283 F.R.D. 587 (D. Or. 2012).

⁶¹ Plans already deny services based on coverage discriminatory coverage exclusions that would push needed services into being considered outside of coverage of the plan or potentially “new” to the plan. See, e.g., *Schmitt v. Kaiser*, 965 F.3d 945 (discussing coverage exclusion of certain hearing services); *N.R. v. Raytheon*, 24 F.4th 740 (1st Cir. 2022) (discussing exclusions based on Autism diagnosis); *Duncan v. Jack Henry & Assocs., Inc.*, No. 6:21-CV-03280-RK, 2022 WL 2975072 (W.D. Mo. July 27, 2022) (discussing exclusions for gender affirming surgery compared to other covered surgeries). Furthering the idea or presumption of not having to cover “new” or “services outside the plan” would likely lead to more discriminatory denials.

provider networks may not limit or deny access to care for individuals with certain disabilities by excluding certain specialties or providers that treat high-cost enrollees. For example, a plan that excluded all developmental pediatricians from their network would discriminate against people with developmental disabilities. Similarly, as touched on above, providers must have accessible medical diagnostic equipment in all facilities. If a plan does not have such providers in their network, then the network is inadequate for and discriminatory against people with disabilities.

The focus on network adequacy is particularly important given the recent Supreme Court decision in *Marietta Memorial Hospital Employee Health Benefit Plan v. DaVita Inc.*⁶² While addressing a different statutory provision, we believe that the case is a clear example of discrimination based on disability and we are disappointed in the decision that the Court reached. Not covering a service that is universally used by disabled individuals is discrimination that 1557 would prohibit--a plan could not choose to exclude epilepsy or HIV medication or choose have no specialists in intellectual and developmental disabilities at all in their networks. This is the kind of discrimination that 1557 explicitly prohibits, where HHS should take additional enforcement actions.

Value Assessment

We appreciate the Department's recognition of concerns over discriminatory value assessment methodologies. The disability community has long been concerned with a particular tool used in value assessment known as the Quality-Adjusted Life Year (QALY). Similar metrics may be known as Disability Adjusted Life Year (DALY) or related terms. In this comment, we will refer to QALYs but intend this to apply to DALYs or other similar metrics. All of these metrics seek to measure how much less value (to society and to the individual) a year of life lived with a disability is compared to a year of life in "perfect health." We are concerned about the use of QALYs in any health-related context. We are most concerned about the use of QALYs in making coverage and access determinations, such as benefit design, formulary design, and utilization management.

The concept of the QALY is concerning on its face; it is based on the assumption that a year of life with a disability is inherently of lower quality and lower value to the individual and to society than life without a disability. The methodologies used to create the QALY pose greater concerns. These methodologies are based on surveys of the general public on their preferences for different health states. There is significant evidence that the general public has negative attitudes toward disability and people with disabilities.

⁶² *Marietta Memorial Hospital Employee Health Benefit Plan v. DaVita Inc.*, 20- 1641 (Jun. 21, 2022), https://www.supremecourt.gov/opinions/21pdf/20-1641_3314.pdf.

Congress recognized that people with disabilities face discrimination from the general public when it passed disability civil rights statutes, including the Rehabilitation Act, Individuals with Disabilities Education Act, and the ADA.

The National Council on Disability (NCD) produced a series of reports in 2019 regarding bioethics and the ways in which the lives of people with disabilities are undervalued in the health care system. NCD recommended that OCR, in conjunction with other applicable agencies, issue guidance that “payment decisions should not rely on cost-effectiveness research or reports that are developed using QALYs” and that “covered health insurance programs should not rely on cost-effectiveness research or reports that gather input from the public on health preferences that do not include the input of people with disabilities and chronic illnesses.”⁶³ We support these recommendations. We also support the NCD recommendation that federal programs, including Medicaid, should not rely on cost-effectiveness research or reports that gather input from the public on health preferences that do not include the input of people with disabilities and chronic illnesses.

We would be similarly concerned about value assessment methods and metrics that measure the cost effectiveness of treatments relative to health outcomes in a way that discriminates on the basis of race, color, national origin, sex, or age. For example, older people are expected to live fewer years than younger people; value assessment metrics that value the years of life a treatment adds may discriminate based on age. Some health care treatments may work less effectively in someone with co-morbid conditions and many racial and ethnic minorities experience health disparities and multiple chronic conditions; a value assessment that measures outcomes of a specific treatment may determine that it is not cost-effective to cover a treatment for racial and ethnic minorities. Such value assessments would be discriminatory and should not be allowed in any health program or activity that receives federal financial assistance. When making life or death health care decisions, the government should not rely on instruments that are based on surveys of the general public. These instruments will reinforce the devaluation and discrimination that Congress has intended to address through civil rights and antidiscrimination statutes.

§ 92.209 - Nondiscrimination on the Basis of Association

We strongly support the provision of the rule that prohibits discrimination on the basis of association. Consistent with longstanding civil rights law, this provision makes it clear that Section 1557’s protections extend to discrimination against associates, partners, or

⁶³ National Council on Disability, *Quality-Adjusted Life Years and the devaluation of Life with Disability* (Nov. 2019), at 15.. https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.

family members of protected class members based on that person's race, color, national origin, sex, age, or disability.⁶⁴ The proposed language mirrors that of Title I and Title III of the ADA, which protect against discrimination based on association or relationship with a person with a disability, as well as regulatory language implementing Title II of the ADA.⁶⁵ This language was included in the 2016 Final Regulations, and then was removed from the 2020 Final Regulations over commenters' protest that the removal would cause confusion both for covered entities and for individuals.⁶⁶

These protections are important, since sometimes the person receiving services from a covered entity is targeted for discrimination because of their association with another person. Preventing this kind of discrimination by association is crucial to addressing health disparities and barriers to care. For example, it would ensure that a health plan does not fail to offer ASL interpretation to the Deaf caregiver of a hearing family member who is undergoing necessary surgery, and it clarifies that a covered entity cannot compel a family member or friend to provide ASL interpretation or reasonable accommodations.⁶⁷

The regulation also clarifies that Congress intended that Section 1557 provide at least the same protections for patients and provider entities. In accord with the ADA, the current regulation recognizes this protection extends to providers and caregivers, who are at risk of associational discrimination due to their professional relationships with patients, including those patient classes protected under Section 1557.⁶⁸ For example, a health insurer is prohibited from refusing a provider's application to join a plan network because that provider chooses to work with groups of individuals that because of their disability are or are perceived to be more likely to contract chronic infectious diseases. Likewise, discrimination against providers who prescribe medication assisted treatment due to their association with individuals with a history of substance use disorder is also prohibited as disability-based discrimination.⁶⁹

⁶⁴ See, e.g., *Holcomb v. Iona College*, 521 F.3d 130 (2nd Cir. 2008) (Title VII); *Larimer v. International Business Machines Corp.*, 370 F.3d 698, 702 (7th Cir. 2004) (ADA).

⁶⁵ 42 U.S.C. 12112(b)(4)(Title I); 42 U.S.C. 12182(b)(1)(E)(Title III); 28 C.F.R. 35.130(g)(Title II) (2010).

⁶⁶ 85 Fed. Reg. 37199.

⁶⁷ See, e.g., Leila Miller, 'I was panicked': Deaf Patients Struggle to Get Interpreters in Medical Emergencies, Stat., May 22, 2017, <https://www.statnews.com/2017/05/22/deaf-patients-interpreters>; *Loeffler v. Staten Island Univ. Hosp.*, 582 F.3d 268, 279 (2d. Cir. 2009) (permitting discrimination claim brought by Deaf father's children who were forced to interpret for him in the hospital).

⁶⁸ 28 C.F.R. pt. 35, app. B (2015) (interpreting Title I and Title III of the ADA to protect "health care providers, employees of social service agencies, and others who provide professional services to persons with disabilities").

⁶⁹ *Mx Group, Inc. v. City of Covington*, 283 F.3d 326, 335 (6th Cir. 2002) (holding a drug and alcohol treatment center that was denied a zoning permit because it provided services to individuals with disabilities).

§ 92.210 - Use of clinical algorithms in decision-making

We support the Department's proposal to address clinical algorithms such that covered entities would be on notice that they cannot base decisions in reliance on discriminatory clinical algorithms. We applaud the Department's prudence in thinking through how such tools may be used to further discriminate against marginalized populations such as, people with disabilities, BIPOC individuals, LGBTQIA people, and those who are multiply-marginalized.

Algorithms promise efficiency in health care, but their potential for harm has been well-documented in other fields such as criminal justice, housing, and employment. In the health care context, algorithms can potentially apply at any stage of the patient-provider relationship: health care enrollment, screening, risk prediction, diagnosis, prognosis, treatment planning, and the allocation of resources.⁷⁰

A. How Algorithms Discriminate

According to a 2021 article in *The Medical Futurist*, there are three main reasons for biased algorithms: judgmental data sets, deeply ingrained social injustices, and unconscious and conscious individual choices.⁷¹ These pitfalls are complex. 'Judgmental data sets' can be a product of incomplete or incorrect data, which can cause measurement error, or, the data set may be skewed in under-including people from a particular demographic background (e.g. containing records of only white males).⁷² "An algorithm may misinterpret a lack of information about minorities as a lack of disease burden and consequently generate inaccurate predictions for the affected groups."⁷³ And algorithms can also perpetuate deeply ingrained social injustices despite facial neutrality (i.e. producing a result based on a variable which does not explicitly take into account a patient's status as a protected class-member). An often-cited example of this is an algorithm which used the patient's previous health care

⁷⁰ *Impact of Healthcare Algorithms on Racial and Ethnic Disparities in Health and Healthcare*, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (Jan. 25, 2022), <https://effectivehealthcare.ahrq.gov/products/racial-disparities-health-healthcare/protocol>.

⁷¹ *A.I. Bias in Healthcare*, THE MED. FUTURIST (September 19, 2019), <https://medicalfuturist.com/a-i-bias-in-healthcare>; See also Donna M. Christensen, et al., *Medical Algorithm Are Failing Communities of Color*, HEALTH AFF. (September 9, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20210903.976632/full> ("Despite their ubiquity, medical algorithms' fatal flaw is that they are often built on biased rules and homogenous data sets that do not reflect the patient population at large.").

⁷² Sharona Hoffman & Andy Podgurski, *Artificial Intelligence and Discrimination in Health Care*, 19 YALE J. HEALTH POL'Y, L. & ETHICS 1, 12 (2020).

⁷³ *Id.* at 15.

spending to determine future risks and thus need for extra care.⁷⁴ The algorithm was less likely to flag Black patients for high risk care management because it assigned lower risk scores to Black patients based on their health care costs.⁷⁵ The algorithm failed to consider that Black patients often face barriers to access and resources to spend money on health care because of entrenched health inequities, not because their needs are any less great.⁷⁶

As noted by the Department, algorithms may rely upon variables that use race and other protected classes (i.e. color, national origin, sex, disability, age) or the algorithms may use variables as a proxy for a protected basis, which can result in discrimination as demonstrated by the example above. Discrimination can also occur where the algorithm cannot account for special circumstances such as if the group or subgroup is small. Even an algorithm with accurate, fully representative data can unintentionally perpetuate discrimination. In one case, an algorithm used patient data to identify patients likely to attend their appointments and created a numerical estimate of no-show likelihood.⁷⁷ This inadvertently created incentive for clinicians to double-book patients with high no-show likelihood.⁷⁸ Researchers found no-show likelihood scores seemed to correlate with socioeconomic status where low-income people had problems with transportation, childcare, or difficulty taking time off of work.⁷⁹ As a result, double-booked patients were likely to receive rushed and inadequate care.⁸⁰

The task at hand is how to best protect individuals seeking health care, knowing that bias is embedded through these factors.

B. Clinical Algorithm-Supported Decision-Making

The preamble explaining Section 92.210 suggests that liability may result from "over-relying on a clinical algorithm in their decision-making, such as by **replacing or substituting their own clinical judgment with a clinical algorithm ... if their decision rests upon or results in discrimination.**" As written, HHS seems to propose precluding a Section 1557 claim against the company who created the

⁷⁴ Steve Vartan, *Racial Bias Found in a Major Health Care Risk Algorithm*, SCIENTIFIC AMERICAN (Oct. 24, 2019), <https://www.scientificamerican.com/article/racial-bias-found-in-a-major-health-care-risk-algorithm/>.

⁷⁵ *Id.*

⁷⁶ *Id.*

⁷⁷ Sara G. Murray, Robert M. Wachter & Russell J. Cucina, *Discrimination by Artificial Intelligence in a Commercial Electronic Health Record--A Case Study*, HEALTH AFF. (Jan. 31, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200128.626576>.

⁷⁸ *Id.*

⁷⁹ *Id.*

⁸⁰ *Id.*

algorithm based on a design flaw and a claim against the provider for implementing a faulty algorithm. The only remaining recourse is user error for a provider "over-relying" on the clinical algorithm as defined above.

One issue is that algorithms are protected trade secrets and thus a "black-box" for which the means of getting the output from the input are entirely unclear.⁸¹ A secondary issue presented by the proposal is how to determine the "over-reliance" on the part of the healthcare provider. The proposal instructs that a care decision should not solely be based on algorithmic output but take into account the specific needs and medical history of the patient. However, the only way to ensure this would be to increase transparency. Patients must have access to the process in which the health care provider reviews the output of the algorithm and what range of decisions the provider can make in reliance of that output. This is required information on which to base an appeal of a wrong decision and allow the patient to access the care they need. The burden should not be on patients to determine that the provider "over-relied" on an algorithm that performed discriminatorily, rather, the burden should be on the provider to prove that their use of a biased algorithm did not result in discrimination. As such, the Department should require transparency in how information from clinical algorithms should be used in decision-making.

We recommend the following:

- HHS not simply recommend, but require that covered entities establish written policies and procedures governing how information from clinical algorithms should be used in decision-making; monitor any potential impacts; and train staff on the proper use of such systems in decision-making;
- Require providers, before implementing clinical algorithms, validate that the tool was tested in different populations to identify hidden biases;
- Establish a baseline understanding that providers must demonstrate, before implementing clinical algorithms, including: how the tool will address a clinical goal, how to identify and correct for potential bias, how to override the tool, and put in place ongoing oversight. We recommend providers do not use algorithmic tools that do not allow them to independently review the basis for a recommendation; and
- Require providers to collect and report comprehensive, disaggregated demographic data such as, claim denials, enrollment, complaints, and outcomes.⁸²

⁸¹ *Id.*

⁸² See Allsbrook, *supra* note 19.

We also request that HHS broaden the 2022 Proposed Rule to include any form of automated decision making system because of the prevalence of automated decision making systems used by covered entities. At a minimum, HHS needs to define the term “clinical algorithms” because it may otherwise be too narrowly construed. For example, some may consider the Crisis Standard of Care Plans cited in the preamble as not “clinical algorithms” under a narrow definition because many were policies or ranking systems rather than automated decisions.

§ 92.211 - Nondiscrimination in the delivery of health programs and activities through telehealth services

We support the specific addition of telehealth in this proposed rulemaking and believe that all entities would benefit from a provision addressing accessibility in telehealth given that a significant number of people with disabilities rely on these services. Telehealth is important for many people with disabilities for whom it may be difficult to leave the house, regardless of a pandemic, but it becomes useless to them if it is inaccessible. Including accessibility of telehealth in the 1557 nondiscrimination rule is necessary so that health care providers and all related entities do not overlook and, directly or indirectly, discriminate against beneficiaries with disabilities because of inaccessible telehealth services.

As the proposed rulemaking mentions, telehealth comes with many benefits such as “lower cost of care and transportation costs, lower exposure to communicable diseases, and access to specialized care including care provided across state lines.”⁸³ There is also a wider network of appropriate specialists and more availability of shorter wait times. However, the accessibility barriers stand in the way of enjoying these benefits. HHS is already aware of many of these barriers: little to no incorporation of sign language interpretation and/or closed captioning, no proxy access that would enable care attendants, guardians, and/or support systems to be with disabled patients, health care portals and material that are not in an easy read format and that are hard for screen-readers to process, etc. These challenges illustrate the need for enforced accessibility standards and a partnership between the covered entities and the disability community, where our input is incorporated from start to finish. This would also entail the provision of training to both health professionals and disabled patients on how to configure telehealth technology for accessibility and how to make the best use of each appointment. While such advancements in telehealth are necessary, we simultaneously recommend not making the mistake of discouraging and replacing in-person visits. Telehealth visits may be beneficial to both patients and providers in multiple ways, but for many people with disabilities visiting in-person maybe still be the more accessible

⁸³ 87 Fed. Reg. 47885.

and preferable choice and should always be an option.

Requiring covered entities to comply with standards like the Web Content Accessibility Guidelines (WCAG) is just the start, the expectation should be for all entities to go beyond and fully incorporate the needs and asks of the disability community in all services in order for there to be a true reduction in health disparity.

The CCD Health Task Force has also created telehealth principles to guide federal public policy.⁸⁴

§ 92.301 - Enforcement mechanisms

In 2019, we opposed the elimination of the former § 92.301 in the 2020 final rule because that change was contrary to the statutory language and Congressional intent. We strongly support the reinstatement of this section and appreciate the clear language in the preamble confirming that enforcement mechanisms include a private right of action. However, as we suggested in our 2015 comments, we believe it is helpful to include language about the private right of action in the text of the rule.

We recommend further strengthening Section 1557's proposed enforcement procedures by explicitly recognizing the existence of intersectional discrimination and to comport with the statutory language of Section 1557: "While the statute incorporates separate existing civil rights laws, it does so collectively in a single provision that recognizes the possibility that someone – say, a Black LGBTQ woman with a disability – could face discrimination based on race, sex, and disability."⁸⁵

We also recommend expanding HHS's authority to find noncompliance with Section 1557 where a covered entity, and not only health programs and activities conducted by recipients and State Exchanges, fails to comply with OCR's information request in a timely, complete, and accurate manner. Data collection, whether required through a specific provision in the final 1557 rule or through HHS's existing authorities or both, will be an increasingly important component of civil rights enforcement under the final rule. HHS must have the authority to require full, timely, and ongoing access to the granular data compiled by covered entities as part of their compliance obligations under the final rule.

⁸⁴ CCD, *Health Task Force Telehealth Principles* (July 2020), <https://www.c-c-d.org/fichiers/CCD-Health-TaskForce-Telehealth-Principles-July-2020.pdf>.

⁸⁵ Jamille Fields Allsbrook & Katie Keith, *ACA Section 1557 As A Tool For Anti-Racist Health Care*, HEALTH AFF. (Dec. 8, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211207.962085/>.

We would urge HHS to explicitly include guidance noting that the statutory language of Section 1557 permits plaintiffs to use any enforcement mechanism “available under” the statute, and thus may assert disparate impact claims under Section 1557. This clarification is especially timely because the district court in *Rumble v. Fairview Health Services* determined that Congress intended to create a new cause of action independent of the enforcement mechanisms for the statutes listed in Section 1557 in part because “[r]eading Section 1557 otherwise would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section 1557 plaintiff depending on whether the plaintiff’s claim is based on her race, sex, age, or disability.”⁸⁶ The district court shared plaintiff’s concerns that if different standards would apply based on the protected class status of the Section 1557 plaintiff, “then courts would have no guidance about what standard to apply for a Section 1557 plaintiff bringing an intersectional discrimination claim.”⁸⁷ Additional clarification from HHS would help individuals and covered entities better understand their rights and obligations.

Change in Interpretation - Medicare Part B Meets the Definition of Federal Financial Assistance

We strongly support HHS’s decision to revisit the interpretation that Medicare Part B meets the definition of Federal Financial Assistance. As we pointed out in our 2015 comments, we believe the statutory text of 1557 specifically does include Part B providers and are glad that the Department has revisited and updated this antiquated definition.

Insurance Exchanges and Group and Individual Health Insurance Markets

We support the HHS’s ’s proposal to prohibit discrimination based on sexual orientation and gender identity throughout the proposed rule, including at §147.104(e) regarding guaranteed availability of coverage, §§ 155.120(c), 155.220(j), 156.125(b) regarding essential health benefits, 156.200(e) regarding qualified health plan participation standards, and 156.1230(b) regarding direct enrollment.

HHS previously proposed to reinstate these protections in the proposed rule “Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment” published in the Federal Register on January 5, 2022. In responding to that proposed rule, we supported HHS’ approach regarding 156.125 and essential health benefits. In the final rule published on May 6, 2022, HHS did not finalize these proposals. We would like to

⁸⁶ *Rumble v. Fairview Health Servs.*, No. 14-CV-2037 SRN/FLN, 2015 WL 1197415, at *11 (D. Minn. Mar. 16, 2015)

⁸⁷ *Id.* at *12.

take this opportunity to support HHS's proposals at the remaining sections.

Thank you for the opportunity to comment on this important proposed rule. We urge HHS to finalize the rule as quickly as possible. Please contact Bethany Lilly (lilly@thearc.org) or Jennifer Lav (lav@healthlaw.org) with any questions.

Sincerely,

Access Ready
Allies for Independence
The ALS Association
American Association of People with Disabilities
American Association on Health & Disability
American Council of the Blind
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Therapeutic Recreation Association
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
The Bazelon Center for Mental Health Law
Brain Injury Association of America
Caring Across Generations
Center for Public Representation
The Christopher & Dana Reeve Foundation
CommunicationFIRST
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation
Family Voices
Justice in Aging
Muscular Dystrophy Association
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Disability Institute
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Down Syndrome Society
National Health Council
National Health Law Program

Paralyzed Veterans of America
Perkins School for the Blind
The Arc of the United States
United Spinal Association