



November 13, 2023

*Submitted via regulations.gov*

Melanie Fontes Rainer, Director  
Office of Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

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

Dear Director Fontes Rainer:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Emergency Management, Employment, Health Care, Long Term Services and Supports, Rights, and Technology and Telecommunications Task Forces and friends write to comment on the proposed rule, *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*. 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 LGBTQIA+ based discrimination and religious intolerance.

This long-awaited proposed rule updates, clarifies, and strengthens the implementing regulation for Section 504 of the Rehabilitation Act of 1973 (Section 504), the statute that prohibits discrimination against otherwise qualified individuals on the basis of disability in programs and activities that receive Federal financial assistance or are conducted by a Federal agency.

The CCD comments address questions regarding continued discrimination in medical treatment, value assessment methods, child welfare programs and activities, website and mobile applications accessibility, telemedicine portal access with assistive technology, accessible medical equipment, and integration. These comments also address supported decision-making, obligations during public health emergencies; raise concerns regarding the use of algorithms and its biased application, the need for greater clarity in the discussion of service animals and the construction of the phrase “solely by reason of his or her disability” among other issues.

As noted in the proposed rule, disabled individuals were harmed and killed during the initial COVID emergency when crisis standards of care were applied. People with disabilities, especially and including those who are multiply marginalized, lost access to necessary medical equipment such as ventilators and did not receive the care they needed. Discrimination in access to care continues with the on-going use of methodologies to assess treatment cost-effectiveness that systematically devalue the lives of people with disabilities.

The proposed updated rules are necessary to ensure disabled peoples’ lives are not valued less than others; that people with disabilities live in the most integrated setting; that children, parents, caregivers, foster parents, and prospective parents with disabilities do not face discrimination in a range of settings; and that websites, kiosks, mobile apps, and medical equipment are accessible to all patients. We submit the following responses to HHS’ questions and include additional concerns and recommendations for your consideration, as well as a table of contents below for page reference.

**TABLE OF CONTENTS**

**A. NEW PROVISIONS ADDRESSING DISCRIMINATION ON THE BASIS OF DISABILITY UNDER SECTION 504** **4**

**A.1 Discrimination Against People with Disabilities in Medical Treatment** **4**

    A.1.1 Medical Treatment (§ 84.56) 4

    A.1.2 Value Assessment Methods (§84.57) 8

    A.1.3 Children, Parents, Caregivers, Foster Parents, and Prospective Parents with Disabilities in the Child Welfare System (§84.60) 11

**A.2 Subpart I – Web, Mobile and Kiosk Accessibility** **23**

    A.2.1 Definitions (§ 84.10) 24

    A.2.3 Exceptions (§ 84.85) 28

    A.2.4 Measuring Compliance 42

**A.3 Subpart J - Accessible Medical Equipment** **43**

    A.3.1 Access Board MDE Standards and Low-Transfer Height 43

    A.3.2 Requirements for medical diagnostic equipment (§ 84.91) 43

    A.3.3 Newly purchased, leased, or otherwise acquired medical diagnostic equipment (§ 84.92) 44

    A.3.4 Requirements for newly purchased, leased, or otherwise acquired medical diagnostic equipment (§ 84.92(a)) 44

    A.3.5 The burdens that the rule’s proposed approach to dispersion or additional dispersion requirements may impose on recipients 49

    A.3.6 The burdens that the rule’s proposed approach to dispersion may impose on people with disabilities (e.g., increased wait times if accessible MDE needs to be located and moved, embarrassment, frustration, or impairment of treatment that may result if a patient must go to a different part of a hospital or clinic to use accessible MDE) 49

    A.3.7 Requirements for examination tables and weight scales. (84.92(c)) 49

A.3.8 Requirements for examination tables and weight scales - recipients with fewer than fifteen employees (§ 84.92(c))	50
A.3.9 Equivalent Facilitation (§ 84.92(d))	51
A.3.10 Fundamental Alteration and Undue Burden (§ 84.92(e))	51
A.3.11 Diagnostically required structural or operational characteristics (§ 84.92(f))	51
<b>B. REVISED PROVISIONS ADDRESSING DISCRIMINATION AND ENSURING CONSISTENCY WITH STATUTORY CHANGES AND SIGNIFICANT COURT DECISIONS</b>	<b>55</b>
<b>B.1 Definitions: Revisions to Subpart A (§84.10)</b>	<b>55</b>
B.1.1 “Auxiliary Aids and Services” (§84.10)	55
B.1.2 “Direct Threat” (§ 84.10)	56
B.1.3 “Most Integrated Setting” (§ 84.10)	57
B.1.4 “Service Animals” (§ 84.10)	57
<b>B.2 Revisions to Subpart C: Program Accessibility (§ 84.38)</b>	<b>57</b>
<b>B.3 Revisions to Subpart D: Childcare, Preschool, Elementary and Secondary, and Adult Education (§ 84.38)</b>	<b>58</b>
B.3.1 Application (§ 84.31)	58
B.3.2 Education of Institutionalized Persons (§ 84.54)	59
<b>B.5 Subpart G: General Requirements</b>	<b>60</b>
B.5.1 General Prohibitions Against Discrimination (§84.68)	60
B.5.2 Maintenance of Accessible Features (§ 84.70)	61
B.5.3 Service Animals (§ 84.73)	61
B.5.4 Mobility Devices (§ 84.74)	65
B.5.5 Direct Threat (§ 84.75)	65
B.5.6 Integration (§ 84.76)	66
<b>C. ADDITIONAL COMMENTS FOR CONSIDERATION</b>	<b>73</b>
<b>C.1 Additional Regulatory Language and Guidance on the Phrase “Solely by Reason of Her or His Disability.”</b>	<b>73</b>
<b>C.2 Section 1557</b>	<b>74</b>
C.2.1. Nondiscrimination in the use of automated decision-making tools and systems	75
C.2.2 Benefit design and related concepts	76
C.2.3 The collection of functional disability data for demographic purposes	76
<b>C.3 Section 504 and Complaint-Driven Compliance</b>	<b>77</b>
<b>CONCLUSION</b>	<b>77</b>

## **A. NEW PROVISIONS ADDRESSING DISCRIMINATION ON THE BASIS OF DISABILITY UNDER SECTION 504**

### **A.1 Discrimination Against People with Disabilities in Medical Treatment**

We strongly support, in their entirety, the new regulatory provisions on discrimination in medical treatment (§ 84.56) and value assessment methods (§ 84.57). The commentary set forth in the Preamble (Fed. Reg 63,395-63,402) presents a compelling rationale and a persuasive legal analysis of the doctrinal basis for these provisions, as well as their particular application to organ transplantation, life-sustaining treatment, crisis standards of care, and participation in clinical research. Given the impact of the pandemic on people with disabilities, and the pervasive examples of discriminatory treatment decisions, denial of access to care, and decision-making criteria that devalued the lives of people with disabilities, these new provisions are essential protections against discrimination. We also endorse, and wish to emphasize the importance of, language that prohibits disability-based discrimination in the informed consent process (§ 84.56(c)(2)(ii)), including the provision of medical advice and the process for providing information on available treatment options. These new regulatory requirements address the key forms of discrimination that were long standing even before the pandemic and that were elevated during the pandemic. The provisions are consistent with both the purpose and case law of Section 504. We applaud the Department of Health and Human Services (HHS) for including these new sections of the regulations.

#### ***A.1.1 Medical Treatment (§ 84.56)***

##### Section 84.56(b)(2) - Denial of Treatment for a Separate Symptom or Condition

- *Medical Treatment Question 1: We recognize that the line between disabilities may in some cases be more difficult to draw than in these examples, and we welcome comments on the best way of articulating the relevant distinctions.*

Individuals with all types of disabilities should have equal access to, and the opportunity to receive, high quality medical treatment, consistent with established professional standards of care. We do not believe that further efforts to distinguish between or define the disability subject to discrimination is necessary or useful. The proposed regulations rightly underscore the importance of providing medical treatment consistent with these standards for all types of disabilities and the individual's informed choice, unless there is objective, individualized medical evidence that the standard of care is contraindicated or would otherwise not be equally effective given the underlying disability.

We believe the concept of underlying disability is appropriate and workable when describing the denial of treatment for a separate condition or symptom (§ 84.56(b)(2)). In addition to prohibited denials of treatment on the basis of specific types or degrees of disability, the failure to provide timely access to medical treatment can also result in disability discrimination, including the failure to provide reasonable modifications required for the individual to access

and benefit from the recipients' services and programs. For example, an individual with epilepsy is hospitalized for heart surgery that is unrelated to their underlying disability. Delays in access to the procedure could exacerbate the person's underlying disability or increase their medical risk, if they are unable to take standing seizure medications. Reasonable modifications to the surgery schedule may be necessary to ensure the individual can access and benefit from necessary medical treatment without experiencing a worsening of their underlying disability.

- *Medical Treatment Question 2: The Department seeks comment on other examples of the discriminatory provision of medical treatment to people with disabilities.*

In addition to the examples provided, the discriminatory provision of medical treatment can occur in hospital emergency departments when individuals with mental health conditions present for diagnostic evaluation and treatment of acute physical health needs. All too often, recipient providers discredit reports of pain or related physical symptoms, presuming instead that the individual with a disability is not an accurate or reliable reporter or is seeking medications. Individuals with a history of trauma who are triggered by the emergency room environment, or whose physical health issues are causing increasing anxiety or emotional dysregulation are particularly at risk for discriminatory treatment. Biased assumptions about the dangerousness of individuals with mental health conditions, combined with the absence of trained behavioral health professionals in the emergency room setting, can result in individuals being subjected to involuntary psychiatric interventions including physical and chemical restraint, instead of requested medical care. These experiences compound individuals' trauma and their distrust of the medical and mental health systems and may discourage them from seeking care in the future. In addition, research indicates that involuntary psychiatric interventions can lead to poor health outcomes.<sup>1</sup>

Like involuntary sterilization, the use of electric stimulation devices (ESD) and the administration of contingent electric shock for behavior modification (as distinct from ECT), is another example of a discriminatory medical decision. This intervention is imposed only on people with disabilities. State and federal agencies, disability professionals, provider associations, family groups, consumer run organizations, and even the United Nations have unequivocally disavowed the use of contingent electric shock precisely because it violates legal, ethical, and professional standards for the care and treatment of people with disabilities. Contingent electric shock is not "treatment." It is not supported by modern research, and as determined by the federal Food and Drug Administration (FDA),<sup>2</sup> electrical stimulation devices create a substantial risk of injury and harm with no reliable evidence of long-term efficacy. Inclusion of this example in the preamble is consistent with the federal government's goal of prohibiting discriminatory medical treatment decisions.

#### Section 84.56(c)(1) Professional Judgment in Treatment

- *Medical Treatment Question 3: The Department seeks comment, including from health care professionals and people with disabilities, on the examples described in this section,*

*whether additional examples are needed, and on the appropriate balance between prohibiting discriminatory conduct and ensuring legitimate professional judgments.*

In addition to examples of prohibited discriminatory judgments, the preamble would benefit from examples of best practices to mitigate the risk of discriminatory judgments. During the pandemic, disability advocates sought, and the Department's Office of Civil Rights approved, complaint settlements that emphasized reliance on individualized assessments and objective medical evidence to reduce the risk of discriminatory allocation of life saving medical care.<sup>3</sup> Additional strategies to reduce the exercise of discriminatory professional judgment include competency-based trainings on disability;<sup>4</sup> a structured process for requesting a second opinion/professional consultation; and the availability of a specially trained, independent review board - with a composition that reflects racial, ethnic, and disability diversity - to consider patient appeals of medical treatment decisions and report publicly on the outcome of those decisions.<sup>5</sup>

Although frequently explicit in nature, discriminatory decision-making in health care can also be grounded in implicit or unconscious bias which is harder to detect and can be cloaked by professional medical judgment. This reality makes the proposed rule, and its prohibition of discriminatory treatment decisions, critical to protecting equal access to medical care for persons with disabilities.

The proposed rule and its construction do not intrude on, or otherwise constrain, the exercise of professional judgment.<sup>6</sup> The preamble makes clear that treatment professionals are not required to work outside their scope of practice or to provide treatment that is futile in light of the patient's treatment goals. At the same time, the presence of conscious and unconscious bias has been well documented within the medical community, including in studies based on self-reported information from medical providers.<sup>7</sup> The basis for prohibiting discrimination in medical treatment also is supported by authoritative research in this notice of proposed rulemaking (NPRM). Given the insidious nature of this bias, and its persistence over time, it is appropriate for HHS to clearly prohibit discriminatory treatment decisions like those described within the proposed rule. Discriminatory treatment decisions cannot be considered a legitimate or appropriate exercise of professional judgment.

#### Section 84.56, et seq. (Medical Treatment)

- *Medical Treatment Question 4: The Department seeks comment from all stakeholders on the risks and benefits of the proposed regulatory choices that the Department has put forth in this section.*

Given the pervasive and long-standing discrimination experienced by individuals with disabilities in access to health care, and the life altering consequences of resulting health disparities, the benefits associated with clearly prohibiting discriminatory medical treatment far outweigh any perceived risks. The proposed regulations place this history of discrimination in a present day medical and legal context, incorporating court decisions, professional research, and

national expertise to support the proposed regulatory framework. Many of these discriminatory policies and practices were laid bare by the COVID-19 pandemic, including the withholding of medical care based on generalized assumptions, stereotypes, and misjudgments regarding the value and quality of life experienced by people with disabilities.

The regulations also recognize and rightly prohibit the kinds of discriminatory policies and protocols employed by many recipients during the pandemic. Examples range from hospitals requiring individuals with certain types of disabilities, like intellectual or developmental disabilities (IDD), to have a do not resuscitate (DNR) order in place, to institutional practices that pressure or steer individuals with disabilities and their agents towards DNR orders or other agreements to remove or withhold lifesaving care. As noted in the proposed rule, recipients also designed Crisis Standards of Care that relied on discriminatory assessment tools,<sup>8</sup> unreliable life expectancy calculations, and protocols that did not provide reasonable modifications needed to ensure equal access to life-saving treatment for individuals with disabilities. The HHS preamble should incorporate more explicit language on the need for reasonable modifications in the use of these tools.

The proposed regulations emphasize the importance of obtaining individuals' informed consent to treatment, but these provisions could be improved by underscoring and cross-referencing recipients' obligations to provide reasonable modifications needed to ensure effective communication and informed choice. As the pandemic demonstrated, this may include modification of hospital visitor policies to allow for a designated support person to facilitate effective communication, offer behavioral support, and assist with access to care. Advocates who obtained these modifications in individual states and recipient facilities did so in large part thanks to complaints involving the federal HHS Office of Civil Rights.<sup>9</sup> Including the example of designated support persons in the regulation's preamble would further underscore the legal obligation of recipients to make reasonable modifications, both individually and program wide, and to ensure effective communication and informed choice for individuals with disabilities seeking medical treatment. For a discussion of the use of plain language as a reasonable modification for a person's disability, see Section A.1.3.3 of our comments. For a discussion of supported decision-making as a reasonable modification for a person's disability, see Section B.5.1.1. of our comments (84.68(b)(7)).

Finally, the preamble should note that cultural responsiveness should be embedded in both the treatment decision-making process as well as access to all necessary treatment options. For people with disabilities, including those from BIPOC communities, accommodating cultural differences and language requirements is necessary in all aspects of medical treatment.

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

We propose the following highlighted additions to the proposed definition of “medical treatment”<sup>10</sup> to ensure it is fully inclusive of the range of conditions and treatment interventions utilized by individuals with disabilities.

“Medical treatment” is used in this section in a generic, nonspecific manner; it is intended to be broad and inclusive. It refers to the management and care of a patient to identify, address, treat, or ameliorate a physical, mental, **intellectual, developmental, or behavioral** health condition, injury, disorder, or symptom, whether or not the condition constitutes a disability and whether the medical approach is preventive, curative, rehabilitative, **habilitative**, or palliative. It includes the use of a wide range of regimens for physical, mental, **intellectual, developmental, and behavioral health** conditions, interventions, or procedures, such as surgery; the prescribing, dispensing, or management of medications; exercise; physical therapy; **clinical, habilitative, and** rehabilitation services; and the provision of durable medical equipment.

#### **A.1.2 Value Assessment Methods (§84.57)**

- *Value Assessment Methods Question 1: The Department seeks comment on how value assessment tools and methods may provide unequal opportunities to individuals with disabilities.*

The COVID-19 pandemic illustrated the urgent need for proposed regulations in the area of value assessments and related medical decision-making. When the health and lives of people with disabilities are devalued by society, and by the medical profession, such rules are necessary to protect individuals’ equal access to care, and to the services and programs of recipients. Individuals from communities of color, where health disparities have already led to high rates of chronic medical and mental health conditions, are at particular risk of experiencing discriminatory treatment decisions, as illustrated by protocols and assessments utilized as part of recipients’ Crisis Standards of Care.<sup>11</sup> The proposed regulations are an important step in prohibiting discriminatory use of value assessments and in remedying the structural barriers caused by recipients’ reliance on assessment tools which prevent equal access to care for persons with disabilities.

We agree with the preamble’s analysis highlighting the deep problems with the Quality-Adjusted Life Year (QALY) value assessment tool. QALY relies on the discriminatory premise that using a treatment to extend the lives of people with disabilities and other chronic conditions is inherently less valuable than using that treatment to extend the lives of people without such conditions. For this reason, and as noted in the proposed rule’s preamble, it has been broadly criticized by disability experts.<sup>12</sup> and its uses limited in federal programs like Medicare.<sup>13</sup> A close analysis of existing federal restrictions on the use of QALYs indicates they are not comprehensive enough to fully safeguard the rights of people with disabilities, which supports the necessity of the proposed rule.<sup>14</sup>



- *Value Assessment Methods Question 2: The Department seeks comment on other types of disability discrimination in value assessment not already specifically addressed within the proposed rulemaking.*

It is not uncommon for value assessments to be used to examine the cost effectiveness of health care services, including medications. Countries including Germany, Italy, and Spain all conduct analyses of prescription drugs using non-discriminatory metrics. So do cost-effectiveness studies within Medicare, since agency use of the QALY as a threshold to determine coverage, reimbursement, or incentive programs was banned by the Affordable Care Act in 2010. The proposed rule need not prohibit the use of value assessments to gather cost-effectiveness data, but it should make clear in the preamble that the collection, analysis, and use of such data must occur in a nondiscriminatory way. For instance, as noted in a 2019 National Council on Disability (NCD) report, QALYs are ineffective at differentiating between clinically significant subpopulations, meaning that differential measurement within or between disease categories may instead reflect subpopulation differences, which may include preferential use of one intervention over others for a particular subpopulation, including individuals with particular disabilities.<sup>15</sup> As such, we agree with HHS that the use of QALYs for “ranking interventions relative to each other within or between disease categories” *should not* be presumed to be a non-discriminatory permissible use of QALYs.<sup>16</sup>

It is also important to note that discriminatory value assessment metrics can lead to additional discriminatory uses that go beyond the devaluation of life extension for people with disabilities. For example, the equal-value Life Years Gained metric (evLYG) modifies the QALY methodology by evaluating life extension benefits on an undiscounted basis. While this approach has been touted by the Institute for Clinical and Economic Review (ICER) as addressing the concerns regarding discriminatory uses of QALY raised by disability groups, the NCD concluded that the evLYG is “not a suitable alternative” for QALY, and, as a metric, is built on much of the same flawed methodology.<sup>17</sup> Even when ICER began using the evLYG, it was meant to be a supplement,<sup>18</sup> not a standalone metric, due to the incomplete picture it paints. Discriminatory denials of drugs or other medical interventions are still possible under the evLYG metric, even if that given intervention would provide a clinical benefit and lead to life extension. In addition, as part of its metrics used to assess changes in quality of life, evLYG continues to rely on health utilities that do not properly account for the variety of unique patient preferences and experiences<sup>19</sup> and discriminate against people with disabilities whose perceived ceiling for quality-of-life improvements is limited by the health utility weights. Because the current proposed rule’s prohibition focuses solely on the use of those assessment tools that discount the value of life extension on the basis of disability, we have concerns that the rule would not prohibit discrimination occurring under the evLYG metric when being used alone for the purposes of making treatment or coverage decisions.

For the reasons set forth above, the proposed rule should include a prohibition on the discriminatory use of assessment tools that devalue either the extension of life years for people with disabilities or the quality of life, including provision of treatment that alleviates suffering

for people with disabilities and other chronic medical conditions. We urge the Department to consider the following amendment to the proposed Section 84.57:

Value assessment methods. A recipient shall not, directly or through contractual, licensing, or other arrangements, use any measure, assessment, or tool that discounts the value of life extension or quality of life on the basis of disability to deny or afford an unequal opportunity to qualified individuals with disabilities with respect to the eligibility or referral for, or provision or withdrawal of any aid, benefit, or service, including the terms or conditions under which they are made available.

- *Value Assessment Methods Question 3: The proposed value assessment provision applies specifically to contexts in which eligibility, referral for, or provision or withdrawal of an aid, benefit, or service is being determined. The preamble discussion of the provision clarifies that the provision would not apply to academic research alone. However, the Department seeks comment on the extent to which, despite this intended specificity, the provision would have a chilling effect on academic research.*

In the past, when the disability community has spoken out against discriminatory treatment decisions, including value-based assessments, the result has been more robust discourse. Rather than having a chilling effect, the continued elevation of these issues, and resulting engagement with the academic community, has stimulated research and innovation in the field. The proposed regulations make clear that it is discriminatory conduct that is prohibited, not the academic exercise of research. They also rightly point out that inclusion in research studies is a critical part of ensuring individuals with disabilities have equal access to, and can fully benefit from, the range of medical treatment being developed in this country.

By enumerating the risks attendant with value assessment tools, including prohibited disability discrimination, HHS can similarly prompt more robust and informed research in this area. NCD has documented numerous potential alternatives to QALYs that, while having their own limitations, appear less likely to embed social biases against people with disabilities, older adults, and people with chronic conditions in their core methodology.<sup>20</sup> Unfortunately, literature reviews of these alternatives find that they are still largely underdeveloped.<sup>21</sup> Some health economists and policy-makers continue to argue that QALY remains “useful” because the research is prevalent and more developed. This narrow view perpetuates a cycle that favors further development of QALYs research despite its acknowledged biases.<sup>22</sup>

By prohibiting the discriminatory use of QALYs for treatment decisions on a broader scale, this proposed rule could accelerate the development of alternatives, including more thoughtful, balanced, multi-method approaches to comparative value assessments that center the perspectives of marginalized subgroups like people with disabilities, inform transparent resource allocation, and, above all, do not discriminate against people with disabilities or other marginalized groups.

### ***A.1.3 Children, Parents, Caregivers, Foster Parents, and Prospective Parents with Disabilities in the Child Welfare System (§84.60)***

The preamble (Pages 63411-63418) and proposed regulatory language in this section will be extremely helpful to the field, especially the intentional focus on the discrimination that is rampant in the child welfare system. These legal requirements are not new and are wholly consistent with the statutory language and longstanding interpretations of the ADA and Section 504 set forth by the U.S. Department of Justice (DOJ) and HHS.<sup>23</sup> That said, our collective experience working with children and caregivers with disabilities and enforcing the ADA and Section 504 through litigation has shown that this clarifying language is much needed, as covered entities have not understood or complied with their obligations under Section 504 and the ADA.

The widespread discrimination in the child welfare system impacts parents, children, and, in cases such as the institutionalization of children, both children and their parents for whom it creates additional barriers to reunification. As the data shows, institutional placements have a disproportionate impact on Black and indigenous children and youth. Once they are removed from their families, they stay in care longer, are segregated more from non-disabled peers, and have poorer permanency outcomes than white children.<sup>24</sup> It is important to address in the preamble and commentary to the regulation how race and poverty impact the discussion of disability discrimination in this context. The statistics are particularly striking, for example, for indigenous populations and Black families, for whom the rates of removal are disproportionately high.<sup>25</sup>

Transparency and equity in this system is long overdue and the discussion of the requirements of the ADA's "integration mandate"<sup>26</sup> in the context of these government actions is critically important.

This strong language from the Preamble sets the tone:

"As a condition of receiving these [Title VI-E of the Social Security Act of 1935] funds, child welfare entities must comply with Federal child welfare law and disability rights laws that require agencies to place foster children and youth in the least restrictive and most family-like setting appropriate to their needs. Congregate care should never be considered the most appropriate long-term placement for children, regardless of their level of disability. This stance is reflected in the Federal enforcement of the integration mandate." (p. 63414)

We strongly support inclusion of this section of the regulation, but ask that the preamble and commentary make clear that the proposed child-welfare-specific regulatory language is not comprehensive of all requirements applicable to child welfare agencies under Section 504 and must not be seen as narrowing or limiting covered entities' existing and long-standing obligations under Section 504 or the ADA. Instead, this proposed language helpfully addresses and clarifies several aspects of discrimination that are particularly common and problematic in

this context to help ensure better compliance and strengthen the existing protections in Section 504. We ask that the Department clearly state that, where an individual with a disability faces discrimination not addressed by these specific provisions, then the broader equal access, equal opportunity, reasonable accommodation, and non-discrimination provisions of the regulation, along with the accompanying defenses, shall apply.

CCD recommends clarifying the statutory language with specifics that will assist government actors and the field in meeting the requirements of the integration mandate and ensuring an end to disability discrimination throughout the child welfare system.

#### Relationship to the “Best Interest” Standard

The following language provides a useful nexus between protections against harm required by child welfare laws and the integration mandate:

“The Department believes that the proposed regulation furthers the best interests of the children involved in child-welfare matters governed by this section. Basing decisions to remove children from their parents or caretakers, to terminate their parents’ rights, or to limit visitation on stereotypes, assumptions, and unsubstantiated beliefs is not in children’s best interests. We therefore believe that the proposed rule both implements the plain requirements of Section 504 and advances the best interests of children and their caretakers.” (p. 63418).

We agree and expand on this concept below in a manner that we believe will make the connection between “best interest” and Section 504 easier to translate into practice.

We divide our comment below into two parts: a discussion of the rights of children with disabilities followed by a discussion of the rights of parents with disabilities. HHS poses three questions in this section that are also addressed below, with Question 1 addressed in Section III (Children) and Questions 2 and 3 addressed in Section IV (Parents).

#### A.1.3.1 Proposed § 84.60 with CCD Additions in Red

CCD has added language to that proposed by the Department below, demarcated in red print and brackets, and provided a rationale for those additions further below.

§ 84.60 Children, parents, caregivers, foster parents, and prospective parents in the child welfare system.

##### *(a) Discriminatory actions prohibited.*

(1) No qualified individual with a disability shall, on the basis of disability, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any child welfare program or activity that receives Federal financial assistance.

[(2) Every child shall be placed in the most integrated setting appropriate to meet the child's needs. The most integrated setting is living with your own family. Children should live and receive services in a family setting unless that setting presents a significant risk to the health or safety of the child that cannot be mitigated through the provision of services and reasonable modifications.]

(3) Under the prohibition set forth in the previous subsections, discrimination includes:

(i) Decisions based on speculation, stereotypes, or generalizations that a parent, caregiver, foster parent, or prospective parent, because of a disability, cannot safely care for a child;

(ii) Decisions based on speculation, stereotypes, or generalizations about a child with a disability[; and

(iii) Initiating or consenting to the placement of a child in a segregated setting, such as in an institution or other facility (including congregate care):

a. when, with services or reasonable modifications, the child can be served in their own home, or a kinship, foster, or therapeutic foster home;

b. without conducting an individualized assessment of the most integrated setting appropriate to meet the child's needs. Placement decisions must be made by an informed team of stakeholders who consider input from the parent and child, using an individualized analysis that is based on multiple relevant factors; or

c. without providing home- and community-based services<sup>27</sup> and supports prior to initiating placement in a segregated setting.]

(b) *Additional prohibitions.* The prohibitions in paragraph (a) of this section apply to actions by a recipient of Federal financial assistance made directly or through contracts, agreements, or other arrangements, including any action to:

(1) Deny a qualified parent with a disability custody or control of, or visitation [with], a child;

(2) Deny a qualified parent with a disability an opportunity to participate in or benefit from [any and all services provided by a child welfare agency, including, but not limited to, family preservation and] reunification services;

[(3) Provide a qualified parent with a disability services that (i) are not] equal to [those] afforded to persons without disabilities; [or (ii) are not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others;]

(3) Terminate the parental rights or legal guardianship of a qualified individual with a disability; or

(4) Deny a qualified [parent], caregiver, companion, foster parent, or prospective parent with a disability [equal] opportunity to participate in or benefit from child welfare programs and activities[, including by failing to provide reasonable modifications as defined by proposed 45 C.F.R. 84.68(b)(7)].

(c) *Parenting evaluation procedures.* A recipient to which this subpart applies shall establish procedures for referring individuals who, because of disability, need or are believed to need adapted services or reasonable modifications[. A recipient also] shall ensure that tests, assessments, and other evaluation [tools and] materials [used for the purpose of assessing or evaluating parenting ability, including through the use of technology like algorithms], [are evidence-based,<sup>28</sup> are conducted by a qualified professional with expertise in the person’s specific type of disability, and] are tailored to assess [actual parenting ability and] specific areas of disability-related needs. [Parenting evaluations must be fully accessible to people with disabilities and shall] not [be based] merely [on] a single general intelligence [quotient or a measure of the person’s disability, rather than their parenting ability. Decisions] regarding the custody or control of, or visitation [with], a child [may not be based on the results of any single test, factor, assessment, algorithm, or other evaluation related to the person’s disability or perceived disability. Rather, risk assessments used for decision-making involving both parents and children must be individualized, based on the best available objective medical evidence, and never used as the sole determining factor when selecting a placement.]

[(d) *Additional prohibitions.* The prohibitions in paragraph (a) of this section apply to actions by a recipient of Federal financial assistance made directly or through contracts, agreements, or other arrangements, and require that:

- (1) Services that are provided as part of “reasonable efforts” under Federal child welfare law include the provision of reasonable modifications as defined by [proposed] 45 C.F.R. 84.68(b)(7).<sup>29</sup> In this context, reasonable modifications must be provided, as needed, to both the caregiver and the child.
- (2) The child welfare agency must ensure that children with disabilities are served in the most integrated setting that is appropriate to meet the needs of the child, as required by [proposed] 45 C.F.R. 84.68(d).]

### A.1.3.2 Children

#### The Integration Mandate and the Presumption of Family Placement

In the proposed language above, we have made several suggested additions to provide clarification to the field about how Section 504 may be implemented in daily practice.

We agree strongly with the statement that “Congregate care should never be considered the most appropriate long-term placement for children regardless of their level of disability,” (p. 63415) and greater specificity is needed to implement this effectively.

In practice, placement decisions are often made by child welfare agency staff who are insufficiently trained, rushed, have limited information on resources and services available to children and individuals with disabilities, and few options to choose from. Providing protections to the child, including competent representation and process steps, and ensuring that agency staff have a sufficient array of placement options from which to choose will help prevent the overuse of institutional placements,<sup>30</sup> “desperation placements” (placement in offices, hotels

and other fully inappropriate settings), emergency shelters, and emergency rooms<sup>31</sup> (all of which are segregated placements).<sup>32</sup>

We have added process considerations (e.g., factors to be considered if a placement in a congregate care setting is considered for a child) and protections against overuse and unnecessary use of congregate care. In addition, we recommend a review process to ensure that placements are as brief as possible, as even a short-term stay in congregate care can cause significant harm.<sup>33</sup> Finally, risk assessments used for decision-making involving both parents and children must be individualized, based on the best available objective medical evidence and never used as the sole determining factor when selecting a placement.

Placement in congregate care can negatively impact both children and parents. A key goal of the child welfare system is to preserve and unify families and the legal requirement is to reunify the child<sup>34</sup> with their family, as soon as it can be made safe to do so, because removal and placement in a segregated non-family setting cause trauma.<sup>35</sup> Both are to be avoided and severely limited when they are necessary.<sup>36</sup> When a child is far from home, it is more difficult for parents to visit, for them to meet the requirements of their reunification plan, and to stay engaged in school and medical appointments, including their continued right under IDEA to make educational decisions for their child with a disability unless their parental rights have been terminated. All of these can prevent parents from achieving reunification goals and prepare for a successful return home. Often children return to their family of origin or foster homes in the community without this critical health and education information.

In order to ensure that states provide a sufficient array of placement options, the regulations and their supporting documents should describe the “continuum of family settings” that a state must provide. That continuum is this: First, the most integrated setting is home with their parents, with supports as needed. Next, properly supported kinship placements, which are critical to keeping the child connected to family, culture, and community. Third, foster care in a family setting, including when appropriate therapeutic foster care. Only once those options have been exhausted, along with the timely provision of reasonable modifications and services (with adjustments as necessary) can congregate care be considered for a child with a disability, and then only for as brief a time as is necessary.

Reasonable modifications include the provision of needed services and supports for both caregiver and child. We suggest adding further clarification about how this affirmative obligation applies in this context, much like in the joint DOJ-HHS technical assistance issued in 2015.<sup>37</sup> The 2015 technical assistance document includes helpful language and examples that we would like to see incorporated into the preamble and commentary to this section – much like how relevant portions of the DOJ Olmstead guidance is referenced or, where appropriate, incorporated into the integration section of the regulation.

Some non-exhaustive, illustrative examples of reasonable accommodations that the Department should include in the preamble and commentary for this section are:  
For family and caregivers:

- Changes in frequency, duration, or location of parent-child visitation
- Hands-on training during a child's medical and early intervention services appointments
- Plain language training materials at appropriate literacy levels
- Adaptations in the manner in which specific training is conducted
- More frequent support from a social worker
- Assistance in understanding and applying behavioral supports for a child who needs these supports
- Training in how to attend IEP meetings and ensure that a child's educational needs are being met
- Modified action planning
- Assessment by a professional who is expert on working with parents with disabilities
- Other modified family preservation and reunification services<sup>38</sup>

For children:

- Case management and Care coordination
- Basic medical needs for children who have complex medical conditions such as in-home nursing supports, hygiene supplies, common first aid and IV supplies, and durable medical equipment
- Services that enable children to live with their families and in supported kinship placements, including: parenting skills classes, household management training, peer support, homemaker services, respite, housing assistance, transportation, cultural brokers and Promotoras<sup>39</sup> education, and community liaisons
- For children with mental health or behavioral related needs:
  - Intensive services to decrease child safety needs, reduce risks, and keep children out of more expensive institutional care. <sup>40</sup> These services include:
    - Intensive Care Coordination (Wraparound)
    - Intensive Home-Based Supports
    - Crisis Stabilization / Mobile Crisis
    - Therapeutic Foster Care

The regulation and commentary must clarify that the recipient of federal funds is ultimately responsible for legal compliance and for the provision of reasonable modifications and services. Child welfare systems are often a complex web of public and private providers. The state must ensure that it provides a full array of services and supports that meet all needs of the children in its care.

Lastly, some states still practice custody relinquishment, meaning that in order for a parent to obtain state funding for placement for a child in a residential setting, they must relinquish their parental rights to the state. This process occurs in cases where there have been no allegations of abuse and neglect. It goes without saying that this practice is antithetical to the accepted standards of child welfare practice. Children should never be separated from their parents in order to receive needed services.



Caselaw and research provide useful guidance about how a state's service array must be implemented. It is considered a failure to provide services when a state's service provision methods result in lengthy service waitlists and provider shortages.<sup>41</sup> Part of the array of services a state provides should include mobile crisis services that connect to home- and community-based services to avoid the need for "crisis placements" that often lead to institutionalization.<sup>42</sup> The system of care shall ensure that services identified in individualized service plans are accessed and delivered in a coordinated and therapeutic manner that is sensitive to cultural differences, and trauma-informed.

A final note about removal processes: Section 504 applies to all stages of the child welfare process. Protection and Advocacy (P&A) agencies<sup>43</sup> report that children with disabilities are not provided basic services needed to participate in the process from its outset. They report disturbing instances, such as a child with hearing loss who was not provided an ASL interpreter during case worker interviews in an abuse and neglect investigation. In another case, the parent showed the case worker the child's IEP repeatedly to prove that a child had an auditory processing disorder, but appropriate accommodations were not provided during the interview. These abuses are exacerbated when there is a language barrier for either the child or family. Children often do not have trained and competent counsel to advocate on their behalf throughout the process.

- *Child Welfare Question 1: "The Department seeks comment on additional examples of the application of the most integrated setting requirement to child welfare programs and welcomes comments on any additional points for consideration regarding integration of children with disabilities in child welfare contexts."*<sup>44</sup>

The most integrated setting for a child with a disability is the most homelike setting appropriate to meet the child's needs, and there is a presumption that the most integrated setting is a family setting. A failure to provide home- and community-based services, including intensive services, is a violation of the integration mandate because it puts children at serious risk of needless institutionalization or segregation.

Decisions to place a child in a segregated setting that are based on speculation, generalizations, or stereotypes or without an appropriate individualized assessment are discriminatory.

HHS must require individualized assessments that are based on current medical knowledge and the best available objective evidence about the appropriateness of the child living with a family (e.g., parents, kin, foster family, therapeutic foster family, or adoptive family), and that include input from the Child and Family Team, including whether or not the child consents to the placement. Additionally, the child's personal preferences should be part of the consideration, when appropriate.

Those making decisions should have experience with and be knowledgeable about the child and also about supporting a child with the full range of disabilities in a family home with (intensive,

if needed) home- and community-based services. Changes in placement require new individualized assessments. Updated assessments must be conducted regularly, including, when a child's placement is in a segregated setting, to determine if a family placement is appropriate.

#### A.1.3.3 Parents

##### CCD's Suggested Additions/Changes with Regard to Parents with Disabilities

As DOJ and HHS have explained, covered entities cannot base decisions about removal of a child on a parent's disability, diagnosis, or intelligence measures (e.g., IQ scores) alone. Rather, they must base such decisions on an individualized assessment of the parent with a disability and objective facts about their parenting abilities.<sup>45</sup> We appreciate and support the proposed regulatory language further clarifying this. To better ensure compliance and recognize the ways in which this is happening now and will likely occur in the future, we recommend that "algorithms" be specifically listed in the regulation as a means by which child welfare agencies, and other covered entities, can violate Section 504 if used or implemented in a discriminatory manner or if it otherwise results in discrimination.

We also ask that the Department insert the following language into the preamble and commentary and provide further explanation with examples:

Risk assessment tools and predictive algorithms are examples of tools that may base decisions for removal on speculation, stereotypes, or generalizations that a parent, caregiver, foster parent, or prospective parent, because of a disability, cannot safely care for a child. An algorithm that uses a caregiver's diagnosis, current or past treatment, or record of disability as a risk factor to increase a person's or family's risk score, for example, is discriminatory and runs afoul of the prohibition on relying on generalizations and stereotypes and of the requirement to conduct an individualized assessment.

Likewise, we ask that the Department include further explanation to make clear that the "direct threat" defense is fact-and context-specific, as we have often seen child welfare agencies misuse, overuse, and misunderstand how direct threat applies in this context. We thus propose adding the following language to the preamble and commentary:

Recipients must not deny family preservation, reunification, or permanency services for disability-based reasons, unless the recipient can establish that the person with a disability poses a direct threat to the health or safety of others in that specific context (i.e., the service) that cannot be mitigated through reasonable modifications or the provision of additional supports.

In addition, one rampant problem in the cases we have seen is a failure or refusal by child welfare agencies to consider all of the supports available to a parent or caregiver with a disability prior to removing a child. For this reason, we ask the Department to make clear:

Very few families parent entirely on their own, and families in the child welfare system are no different. Child welfare agencies should consider natural supports when analyzing the ability of the family of origin to parent, including relatives, neighbors, friends and their religious community.

- *Child Welfare Question 2: The Department invites comment on this list of prohibited activities in the child welfare context, especially on whether commenters believe it is complete. (emphasis added)*

We are grateful for HHS's effort to address this important issue. Despite their longstanding obligations under Section 504 and the ADA, child welfare authorities too often separate children with and without disabilities from their disabled parents. Separation may traumatize parents and children even if reunification efforts are ultimately successful. The child welfare system must treat children and families in a manner consistent with relevant civil rights law. For this reason, social services agencies must not be permitted to subject children and their caregivers to an experience that is almost inevitably traumatizing unless conditions in their family are dire and irreparable. Removal should take place only where that setting presents a significant risk to the health or safety of the child that cannot be mitigated through the provision of services or other reasonable modifications to parent and child.

Too frequently, the adults in families with disabled members are held to higher standards than foster, adoptive, or institutional caregivers. This is particularly true for parents with disabilities. CCD members have encountered situations where child welfare agencies became overly concerned about a person with a disability's capacity to parent because of stereotypes and assumptions about people with certain conditions or failure to consider the natural and paid supports available or already in place. This leads to unnecessary removals, overly slow reunifications, and the suffering these things inevitably cause.

Even where it is necessary for child welfare agencies to intervene in a particular family's situation, we share HHS's concern that too few states make appropriate efforts toward maintaining children in their families of origin and reunification for parents with disabilities. Child welfare agencies rarely provide the services and modifications necessary for these families to thrive after an encounter with the child welfare system. CCD members have encountered this problem across disability categories, but it seems particularly common in the case of parents with intellectual, developmental, or mental health disabilities. These overzealous removals and lackluster reunification efforts, both discriminatory, can lead to preventable terminations of parental rights. Severed family ties are a loss for any child, even when there is no way to make their family safe in the foreseeable future. Moreover, termination may be particularly costly for children who have or may later develop hereditary disabilities. Cutting these children off from their families of origin may separate them from older relatives who are potential role models and sources of information for living with their disabilities. The frequent, discriminatory exclusion of disabled adults from the ranks of external

caregivers means that these children are not likely to get that information from the caregivers they encounter in the child welfare system.

While the Department's list is fairly comprehensive, we suggest two additions. First, just as HHS proposes to explicitly prohibit child welfare agencies from basing parenting capacity decisions on IQ alone, we ask that the Department prohibit parenting capacity decisions based solely on the fact of a parent being under legal guardianship. In some states, guardianship is effectively the default status of adults with intellectual and developmental disabilities (IDD) and serious mental health disabilities. It is widely overused in these populations, with weak due process protections and far less access to counsel in many jurisdictions than the rights at stake warrant. Guardianship is often applied to adults in the early stages of recovery from a traumatic brain injury where a young, healthy individual who did not anticipate being incapacitated has not used tools like powers of attorney to select someone to be their surrogate decision-maker in the event of an emergency. These guardianships are not always revisited later in the recovery process, when the individual may have regained a significant amount of decision-making capacity. Similarly, some states accept substance use as grounds for adult guardianship. The person may enter long-term recovery and still have a difficult time getting restored to legal capacity.

Child welfare agencies often assume a disabled parent's guardianship signals broad incapacity, particularly if it is full, plenary, or covers all rights pertaining to the person. A disabled adult's guardianship often demonstrates that the relevant state applies guardianship to virtually every person with a disability whose competence is questioned by the state or a third party regardless of whether the questioning is reasonable or in good faith. A guardianship with broad powers is often a symptom of overtaxed court systems where adjudicators lack the time and resources to consider the strengths and weaknesses of defendants in guardianship proceedings in an individualized way. On the grounds of a discriminatory guardianship system, the individual is deprived of the opportunity to parent, and both parent and child are subjected to the trauma of lasting separation. To prevent stereotypes and assumptions about decision-making capacity and from reinforcing those about parenting ability and prevent states' failures to protect their residents' basic civil rights in guardianship proceedings from compromising further rights and interests, the Department should explicitly prohibit states from making decisions about parental rights solely on the basis of a parent's guardianship status.

Second, HHS should clarify that failing to provide reasonable accommodations and reasonable modifications for parents in child welfare processes, such as during investigations, parenting assessments and evaluations, and reunification, should equate to the child welfare agency failing to make reasonable efforts to preserve the family of origin. Child welfare agencies frequently make no real effort to provide supports and modifications that would avoid discrimination and empower parents with disabilities to fulfill the conditions of reunification and keep their children. Many of these organizations are uninformed about their obligations under federal disability rights statutes. Making this requirement explicit, ideally in the text of the rule, would help to put them on notice about their obligations. It might result in more

prompt compliance, sparing families touched by the child welfare system immense suffering and reducing the costs and effort associated with enforcement.

- *Child Welfare Question 3: The Department seeks comment on how agencies would implement these referral procedures, ensure that service providers use the methods described, and prohibit the use of IQ alone as the basis for a parenting assessment.*

We are grateful for the Department's attention to this important issue. People with IDD are often deprived of the opportunity to parent their children despite a growing body of evidence that IQ is a weak predictor of parenting ability. Prohibiting the use of IQ alone to determine parenting ability will help prevent the avoidable destruction of family units and the harm this causes to children, parents, extended families, and communities. Even if IQ tests are not used, the presence of an IDD diagnosis should not be used as the sole determination of competence. We also hope the Department will add an analogous provision and commentary in the preamble on the use of a parent's legal guardianship to the final rule as previously described.

As previously stated, CCD members believe parents with disabilities should not be held to higher standards than nondisabled parents or alternative caregivers. In one case in Oregon, the child welfare system removed a child from his parents, both with developmental disabilities, for benign, non-endangering behaviors. For instance, child welfare authorities criticized the parents for needing to be told to put sunscreen on the child's arms, for living in a house paid for by the father's parents, and for offering the child fried chicken nuggets to eat, instead of boiled chicken. Moreover, parenting virtually never takes place in a vacuum. Adults who are responsible for children, whether as their parents of origin or adoptive parents, stepparents, foster parents, or kinship or fictive kinship caregivers often turn to a wider support network for help. This may include family, friends, neighbors, paid caregivers, and social and religious organizations. Parents, especially parents of young children, are often encouraged to rely on their "village" to help raise their families. It should be accepted that parents with disabilities, including physical, intellectual, developmental, and mental health disabilities, will often do the same thing. Natural and paid supports, including those the parent is already using and those available that the parent expresses willingness to use, should be incorporated into the assessment of parenting ability. Child welfare agencies should not ignore possible and existing support networks and evaluate parenting ability in isolation.

To ensure that child welfare agencies can make a comprehensive assessment of the paid supports a parent with an intellectual disability is or could be using, and ensure that those supports are in place, child welfare agencies will need to familiarize themselves with the adult home- and community-based service (HCBS)<sup>46</sup> systems in their states. They will also need to learn how to support parents in navigating these systems to get the services they need to successfully raise their children. HHS should include language in the final rule stating that it is discriminatory for child welfare agencies to fail to support parents in seeking services from these systems when that is necessary for the child to safely remain with their family of origin. The facilitation of HCBS for the parent, the child, or both should be explicitly framed as a reasonable modification that will sometimes be required under the Rehabilitation Act. This

language should apply to both federally- and state-funded services, as they are all part of the child welfare agencies' programs and activities.

Similarly, child welfare agencies should always assess parenting ability in terms of functional capacity with all available supports the parent is willing to use. If a parent can safely parent with reasonable accommodations and other supports, then they can safely parent and functional capacity should not be used to assess parenting ability. Moreover, HHS should require child welfare agencies to consider not just the functional capacity the parent has at the time of initial contact with the child welfare system but also the functional capacity the parent might build through the use of any services, training, or rehabilitation the parent is willing to accept. Because solutions to the challenges of parenting will necessarily be individualized, the Department should encourage child welfare agencies to take creative, multidisciplinary approaches.

Child welfare agencies should be required to build networks of professionals sufficient to provide the reasonable accommodations, auxiliary aids and services, and rehabilitation some parents with disabilities may require. Occupational therapists and others in the rehabilitation fields, Centers for Independent Living, Parent Centers (who assist parents of children and youth and young adults with disabilities), psychiatric rehabilitative services, and peer support workers are among the resources child welfare agencies should be able to use to assist families. However, any list of required or suggested resources HHS creates will necessarily be non-exhaustive and would be best worded "included but not limited to." This would encourage state adherence to the purpose and spirit of the Rehabilitation Act and other federal disability rights statutes: practical solutions that will meet the needs of specific people.

HHS should encourage states to seek broad stakeholder involvement in the design of policies and procedures for child welfare agencies in order to better serve families with disabled parents. Self-advocates, family members, and developmental disability professionals are all essential to this process. Perspectives from outside of the state agencies may challenge the negative stereotypes and assumptions about the parenting capacity of people with disabilities endemic within them.

Parenting assessments must be fully accessible. They should have a narrow focus on what is essential to parenting. Parenting assessment tools should not be worded in any way that disadvantages broad swaths of the disability community without addressing the actual parenting task. For example, parents need to ensure that their children attend school and get to medical appointments, but there are many ways a family might handle those things besides one or more adults in the household having a car and driver's license. This is especially important for people with disabilities, such as epilepsy that can restrict their ability to drive. Using ridesharing or public transportation, living in a walkable community, or getting rides from consistently available loved ones or friends should be treated as equally acceptable provided they achieve the purpose of meeting the child's needs. Using decision-making support in making abstract decisions in the life of a child may also be necessary for some parents. The goal in making these decisions is the child's wellbeing, and supported decision-making should be

regarded as an equally acceptable way to achieve that goal, as described in Section B.5.1.1 (Reasonable Modifications and Supported Decision-Making (§ 84.68(b)(7))) of these comments.

Parenting assessments must evaluate parenting ability in light of any reasonable accommodations, auxiliary aids and services, and natural supports the parent uses or is willing to use to complete parenting tasks. Parents involved in child welfare systems should be provided with accessibly formatted documents (complying with current Section 508 and WCAG standards) if that is a disability-related need, not penalized for using or requesting them. Where a parent with a disability has independently found ways to meet their child's needs, such as relying on a service animal to take a child out in public or seeking help with household tasks from natural supports, parenting assessments should note this as resourcefulness that will promote the family's wellbeing. Where parents have not found the necessary supports on their own, child welfare agencies should be required to connect parents to all available tools.

All aspects of child welfare processes must also be accessible. The Department should make clear to child welfare agencies that this includes parenting classes and their written materials, any forms or assessments parents are required to fill out, and any information provided to parents. HHS should state that accessibility includes but is not limited to meeting the written communication needs of people with sensory disabilities. Plain language and easy read materials are also essential. Some parents may require other learning accommodations. These may include taking more time to explain certain concepts, repetition in training parenting skills, hands-on demonstrations, and individualized attention as opposed to group instruction.

## **A.2 Subpart I – Web, Mobile and Kiosk Accessibility**

### Introduction

This rule will have a profound impact on a significant proportion of our population by requiring recipients to plan for the diversity of ways that people use the internet to access public services, programs, activities, and information. People who are blind may use screen readers to convert code to audible text and use a keyboard to navigate. People with low vision may use screen magnification and rely on high contrast to visually perceive content. People with manual dexterity disabilities may use switches or gestures to navigate a website or app. People who are deaf or hard of hearing benefit from captioned videos or ASL interpretation. People with cognitive disabilities benefit from websites and apps that are clearly organized, do not require puzzle solving, and that allow users ample time to complete tasks. People with speech disabilities may rely on text-based alternatives to voice communication modes and require alternatives to recorded responses. People with seizure disorders often cannot use websites or video content that produce rapid and unexpected flashes or animation. People with print and learning disabilities may use speech-to-text and text-to-speech software to facilitate reading and writing. Websites and mobile applications must be accessible and provide interoperability with assistive technology.

This rule is vitally important for people with disabilities to have equal access to healthcare services and community living – whether they are blind, deaf, hard of hearing, or deafblind or have low vision, seizure disorders, limited manual dexterity, speech disabilities, learning disabilities, or cognitive disabilities. Digital information and services are easier and quicker to access and provide benefits to federal funding recipients by enabling the rapid distribution of information and reducing barriers of distance and time of travel. However, for too long, the benefits of health and human service systems’ digital infrastructure have been denied people with disabilities because so many websites and mobile applications have been designed and developed in a way that excludes people with disabilities, including those who use assistive technology.

This subpart could dramatically alter the way that people with disabilities are able to live in their communities and will contribute to further community integration in the full spirit of the Rehabilitation Act and the Americans with Disabilities Act. We are grateful that this NPRM provides a solid starting point for regulating digital accessibility, but this rule must be improved to protect fully the rights of people with disabilities. This regulation has the potential to dramatically shift the accessibility landscape for individuals and recipients tasked with complying with the accessibility requirements. **A strong rule will clarify that accessibility is the expectation, not the exception, across all programs and services and will bring recipients’ many vendors and third-party partners into compliance as well.** We urge the Department to adopt the changes that we describe to Subpart I in these comments to eliminate confusion and loopholes.

#### ***A.2.1 Definitions (§ 84.10)***

- *Web Accessibility Question 2: The Department requests comment on whether a definition of “kiosks” is necessary, and if so, requests comment on the Department’s proposed definition in § 84.10 and any suggested revisions to it.*

We greatly appreciate the Department’s inclusion of kiosks alongside mobile apps and websites. As the Department describes, kiosks are frequently used in medical and other facilities to check in patients, schedule laboratory visits, and process payments.<sup>47</sup> We urge the department to ensure that the definition of kiosks is also inclusive of informational kiosks or kiosks that do not necessarily involve a transaction between the provider and the patient. For example, digital kiosks are often available in medical buildings as a substitute for a print or wall-mounted directory of office locations. Some elevators use an inaccessible touchscreen to select the destination floor and to tell the user which set of doors to use. Further, we encourage the Department to include in the final rule examples of other common inaccessible kiosks, such as self-service coffee machines<sup>48</sup> and vending machines that are available to the public and that frequently include an inaccessible touchscreen or visual display that requires the user to be able to see and touch the screen to perform the transaction.

#### ***A.2.2 Requirements for Web and Mobile Accessibility General (§ 84.84)***



#### A.2.2.1 Proposed WCAG Version

- *Web Accessibility Question 4: Are there technical standards or performance standards other than WCAG 2.1 that the Department should consider? For example, if WCAG 2.2 is finalized before the Department issues a final rule, should the Department consider adopting that standard? If so, what is a reasonable time frame for recipient conformance with WCAG 2.2 and why? Is there any other standard that the Department should consider, especially in light of the rapid pace at which technology changes?*
- *Web Accessibility Question 9: Is WCAG 2.1 Level AA the appropriate accessibility standard for mobile apps? Should the Department instead adopt another accessibility standard or alternatives for mobile apps, such as the requirements from Section 508 discussed above?*

**The Department should adopt the most recent WCAG standard, which is WCAG 2.2, Level AA, for all recipients** - The W3C Web Content Accessibility Guidelines are international standards informed by experts in digital accessibility. The multiyear consultations for each new standard ensure that the standards are achievable, effective, and clear, and regular updates ensure that they meet the current state of technology. WCAG 2.2, Level AA, is the most recent standard since it was published as a “W3C Recommendation” web standard on October 5, 2023. As the Department notes, there are certain changes between WCAG 2.1 and 2.2; however, they are limited. The changes would eliminate one success criteria and add six Level A and AA criteria, such as setting a minimum target size and providing alternatives to dragging motions. The proposed criteria are achievable and will provide substantial additional benefits to people with disabilities over WCAG 2.1. Considering that the new standard significantly precedes publication of the final rule, and that the Department intends to provide a period of time for recipients to become familiar with the rule, we do not think that awareness of WCAG 2.2, Level A and AA, presents a significant obstacle to adopting the most recent standard. To create a strong, up-to-date standard, we urge the Department to adopt the most recently adopted WCAG standard for all content, including mobile apps, without exception and for all recipients, regardless of size, to maximize access for all people with disabilities and ensure that recipients meet standards that account for changes in typical web and software development practices. We further strongly encourage the Department to update the rule regularly as new standards emerge.

In addition, the Department should also consider other web accessibility standards and guidelines such as the Authoring Tool Accessibility Guidelines (ATAG)<sup>49</sup> and the User Agent Accessibility Guidelines (UAAG).<sup>50</sup> These guidelines provide additional information that developers should follow in making authoring tools, browsers, and multimedia players more accessible. Recipients frequently employ these tools even if they do not create them, so these guidelines would support procurement of accessible tools and content from vendors. In addition, the ATAG requires the creation of elements that facilitate third parties uploading more accessible content, addressing the concerns underlying some of the proposed exceptions.

#### A.2.2.2 Recipient’s Use of Social Media Platforms

- *Web Accessibility Question 7: How do recipients use social media platforms and how do members of the public use content made available by recipients on social media platforms? What kinds of barriers do people with disabilities encounter when attempting to access recipients' services via social media platforms?*

We appreciate the Department considers social media content posted by recipients to be web content that must be made accessible. Recipients use social media platforms to provide health information, scheduling information, and notification about changes to operating procedures. These posts allow the public to benefit from public health messaging programs and actively benefit from the programs and services of individual providers. For example, public health departments may create videos encouraging residents to get immunizations or engage in other public health practices.<sup>51</sup> Hospitals may share links to new programs.<sup>52</sup> Housing services providers may post flyers about upcoming events or application deadlines.<sup>53</sup> These posts should use plain language, include image descriptions, and provide captions and audio descriptions, so that people with disabilities have access to the same information at the same time and in the same places as people without disabilities.

#### A.2.2.3 Mobile Applications

- *Web Accessibility Question 8: How do recipients use mobile apps to make information and services available to the public? What kinds of barriers do people with disabilities encounter when attempting to access recipients' programs and activities via mobile apps? Are there any accessibility features unique to mobile apps that the Department should be aware of?*

**Websites, mobile apps, kiosks, and all forms of ICT must be accessible to people with disabilities** - Recipients use apps for a wide array of purposes. For example, doctors and medical providers use third-party and self-developed apps to allow patients to make appointments for a variety of services, read test results, pay bills, communicate with their providers, conduct telehealth video visits (including 24/7 video calls with a nurse that do not require an appointment), find urgent care locations, check in for appointments, review care instructions, provide caregivers with access to their health records, and more.<sup>54</sup> Many doctors give patients medical equipment that is connected to an app<sup>55</sup> or ask them to use fitness tracking apps that can be linked to an electronic health record. Some health insurance companies provide patients with tablets that include apps for managing and monitoring weight and blood pressure.<sup>56</sup> As such, we strongly urge the department to make the whole rule apply to mobile apps – and, as we will explain, we broadly oppose the inclusion of any exceptions.

This rule will make a significant impact on the lives of millions of people with disabilities in the United States by covering websites, mobile apps, and kiosks. Nevertheless, because there are a wide range of digital software and hardware tools that pose accessibility barriers, we propose that the department should go further to cover “Information and Communications Technologies.” The Federal government’s Section 508 rules appropriately cover this more

comprehensive set of technologies in recognition that effective communication and equal access are important regardless of the technological means of access. Like kiosks, websites and mobile apps, technologies like desktop apps and email communications are also very important components of recipients' activities and program delivery, and doctors often prescribe hardware like connected glucose monitors, smartphones, and fitness trackers for the management of diabetes. By including a broader scope of digital technologies, the Department would also increase access to employment in health and human services as employees are often expected to use a wide range of information and communications technologies in the course of their work.

#### A.2.2.4 Requirements by Recipient Size

- *Web Accessibility Question 11: How will the proposed compliance date affect people with disabilities, particularly in rural areas?*

**The compliance timeline should be shortened, especially for new content** - The proposed compliance timeline is exceptionally long, considering the rapidity with which websites and mobile apps are updated and how frequently web content is created. The Department makes no distinction between new content, which for the most part can be made accessible immediately, and existing content which may take some time to audit and remediate. The compliance timeline does not consider that many entities are already largely in compliance with the proposed rule. Moreover, for children with disabilities in a head start program, a three-year compliance period would be longer than the time they will be in the program. In addition, two years is an exceptionally long time in the course of treatment for chronic medical conditions, such as cancer. Missing information about post-operative care during that time period can have a significant effect on a person's recovery. We urge the department to shorten the timelines. At a minimum, new content should be made accessible within 6 months while existing content may need a longer compliance period unless individuals with disabilities request access to that content at an earlier date.

**The Department can help small entities by providing ample technical assistance** - Many entities, especially small entities, will benefit from an aggressive public awareness campaign, training, and technical assistance. Each entity will need to inform their legal team, IT team, content managers, and product vendors of their compliance responsibilities. Content managers, IT professionals, and vendors will need training in understanding WCAG and how to test for and implement it. We urge the Department to consult with the disability community and to work with all available partners, including the ADA National Network and Assistive Technology Act Programs, to provide ample free or low-cost training. Entities should be informed through all available channels that this rule is going into effect, including professional associations for health and human services providers. Given that lack of knowledge is a commonly cited reason for website and application inaccessibility, technical assistance must be available to ensure all entities, including the smallest ones, have the knowledge needed to comply.

### ***A.2.3 Exceptions (§ 84.85)***

**The undue burden and fundamental alteration defenses obviate the need for exceptions, which undermine the goal of the regulation and overlook that accessibility is usually achievable.** In general, we strongly urge the Department to eliminate the proposed exceptions. The difficulties named in addressing each of the proposed exceptions do not substantively add to entities' existing defenses where compliance would result in undue burden or fundamental alteration. Instead, the proposed exceptions generate substantial confusion about what must be made accessible and make the rule less consistent. They will have significant impacts on whether people with disabilities can fully participate in healthcare, human services, and educational activities funded by the Department, and they will effectively enshrine the status quo into law. These exceptions are confusing, unnecessary, and burdensome, and they undermine the intent of the regulation.

Today, the Department holds that entities must make their websites accessible, yet people with disabilities still frequently encounter access barriers. Thus, people with disabilities must request that websites be made accessible or provided in an alternative format. **It is a substantial burden on people with disabilities to continue to disclose their disability, to request that every exempted recipient make their services accessible, and to wait until a time that a recipient's employee is available to provide assistance. In reality, people with disabilities often forego the service or rely on a companion for assistance instead of requesting an accessible version.** Because filing complaints and requesting materials is burdensome, entities may not be aware of the extent to which people with disabilities are being excluded or disadvantaged in the use of their websites or apps.

It is further unrealistic to expect that entities will consistently remember to provide individual patients or clients with disabilities with a special alternative to their otherwise automated medical bills or that schools will be able to entirely remediate all documents, websites, apps, and other services used in a given class within five days. Entities currently have an unsatisfactory track record on both accounts. Rather, recipients often rely on vendors, contractors, and automated systems to deliver web content, and it is those entities that must be informed, conduct testing, remediate the product, and turn the accessible product around to the school, recipient, or individual in a timely manner. The proposed exceptions on third party posts and linked content muddy the water by casting doubt on whether these vendors, contractors, and other third-party partners must provide accessible content to and on behalf of covered recipients. Designing for accessibility is most effective and timely for the recipients when done on an ongoing basis rather than on request.

The goal of this regulation is to make websites and applications used by recipients fully accessible to people with disabilities. Websites and applications that are born accessible benefit people with disabilities and do not create a remediation obligation for recipients. In spite of this, the seven proposed exceptions ensure that people with disabilities will continue to be excluded from certain content. They will also make the job of recipients harder by requiring

them to remediate content on a case-by-case basis, including content that is produced by an external entity or automated system. Third parties that contract with or even partner with recipients must share some of the responsibility for making their content accessible, and recipients must have the responsibility to select accessible content that is integrated with or linked to on their websites or apps.

From this point forward technology needs to be born accessible. Over time, inaccessible content will become less and less common. It will take work to shift expectations, roles, workflows, and knowledge about accessibility, but the final product of this work is greater access to healthcare, education, and other human services funded by the department. Moreover, accessibility is achievable in the current environment with the growing availability of accessible website templates and tools that prompt content managers to add accessibility features. The future of AI could lead to new technologies that make accessibility even easier. The proposed exceptions are focused on what is hard now, and they do not consider future improvements. Instead, they enshrine current difficulties across the life of this regulation, which may very well last decades, and set a bad precedent for other regulations. This regulation must drive new technology to be born accessible. If we achieve a state where accessibility is the default, inaccessible content will become less and less common as it is deprecated. On the other hand, if we exempt certain categories of content, we will ensure a large volume of content remains inaccessible.

To make an undue burden or fundamental alteration determination, entities may need additional guidance to know when and how they can or cannot invoke an undue burden or fundamental alteration defense. In addition, we recommend that the Department require entities claiming undue burden to provide an accessibility statement identifying the inaccessible content, a reliable contact for people with disabilities seeking assistance, and a timeline on which people with disabilities can expect requested content to be made accessible or provided as an alternative format. They should also create and publish a remediation plan identifying the timeline on which inaccessible content will be made accessible in accordance with the entity's anticipated administrative resources.

In response to the following questions, we discuss issues relevant to recipients of federal funding through the Department of Health and Human Services. The proposed exceptions align with other recent federal proposals for regulating accessibility under the Americans with Disabilities. As such, these proposed rules will have different effects for different covered entities and the beneficiaries of their services and programs. For additional information and examples about the effect of these proposed exceptions, we refer the comments submitted by 264 members of CCD and other disability organizations in response to the Department of Justice's Title II NPRM.<sup>57</sup>

#### A.2.3.1 Exception: Archived Web Content

- *Web Accessibility Question 18: What would the impact of this exception be on people with disabilities?*

**Eliminate the exception for archived web content** – The proposed definition of “archived web content” is expansive and covers a wide range of useful and important information, not just information that is outdated, superfluous, or replicated elsewhere. This exception will result in people with disabilities being denied access in perpetuity to a range of important historical information. Unfettered access to all current and archived public documents is foundational to an individual and the public right to know, the right to petition, and to engage in every facet of American Democracy, and should not be abridged on the basis of disability or any other exclusionary reason. Public records, as the name implies, even when archived, should be readily available to all members of the community. However, this is decidedly not the case: Currently, archived records are regularly available in inaccessible formats for people with disabilities, and requests for accessible copies are often not provided in a timely manner. The final rule must put this right rather than sanction and perpetuate it for time immemorial.

Unfortunately, the NPRM creates an exception that would exempt recipients from ever having to make any archived materials digitally accessible. This is nonsensical and overly sweeping. The message it sends is deeply disturbing and inconsistent with disability rights law – namely that people with disabilities who need to access information in accessible formats quite simply have no real need, no business, nor the right to do so.

We recognize the difficulty in making a large number of archived documents fully accessible especially in one fell swoop. However, we likewise strenuously reject the premise the proposed exception seems to be based on which is that most archived materials can never be made publicly available in a digitally accessible format in a way that is planful, reasonable and achievable.

Instead, the proposed exception would levy an unfair and unworkable “access to information tax” on individuals with disabilities that would never be imposed on any other class of people. Under this exception, the person must know the exact document they are looking for when requesting a converted copy. However, a person may not know precisely what they are looking for if they are seeking the answer to a question. For instance, a person may need to better understand a medical condition with which they have been diagnosed and will want to search broadly through an archive of medical publications.<sup>58</sup> In such a circumstance, they will be unable to name the exact document they need until they have spent some time in the archive whose documents are inaccessible. As a result, people with disabilities should have full access to all archived documents available to all other researchers.

Additionally, we note the definition of archived content is expansive. Recipients must by law make numerous documents used “exclusively for reference, research, or recordkeeping” (especially recordkeeping) available to the public. For example, a state council of health officers may retain years’ worth of public meeting records.<sup>59</sup> In some cases, there are financial penalties for not making records available for public inspection. Such an exception undermines these laws by allowing as many as 1 in 6 members of the public to be excluded in whole or in part

from such information. Even if they are archived, these local records may need to be frequently accessed to fulfill job responsibilities or participate in civic discussions.

- *Web Accessibility Question 19: Are there alternatives to this exception that the Department should consider, or additional limitations that should be placed on this exception?*

**Making archival documents accessible is generally achievable** - We strongly contend that recipients will be able to make their archives accessible in a manageable and efficient process. If a recipient had a truly unmanageable amount of archived web content, they would qualify for an undue administrative burden defense, dependent upon their budget, number of staff, and other factors. To the extent that recipients can claim that exception, they should then be required to create a schedule to convert archived documents in a way that prioritizes the needs of their constituents. They may make a distinction between record keeping documents (such as those related to planned construction projects, needs assessments, and service changes) and out of date web pages (such as past events pages, that may be maintained on the archive section of the website solely to create a historical record). They might start with prioritizing more popularly accessed records or more chronologically recent documents.

In addition, the proposed text of the rule currently is unclear about whether upon request, the recipient must provide an accessible version of the document in an accessible format in a timely manner. If this exception is permitted in any capacity, the department should define the time frame for providing access to the documents, so a person with a disability is not waiting indefinitely to receive the documents. This time frame must not be longer than a few business days. Additionally, this process and time length should be posted clearly on recipients' websites so the requester understands the time frame they must wait before receiving the accessible document. However, we note that requesting inaccessible documents is the status quo, and people with disabilities currently do not receive effective access to documents in a timely manner, and in some cases, the alternative version is not as effective as the original document. In addition, even if this exception is put into place, it should not be applicable to future archived documents. In other words, when documents are created by recipients moving forward from the official start date of the regulation, the recipient must ensure that all future created documents that move into archived systems are made accessible to prevent future access barriers. The recipient must ensure that the systems that archive any documents must not convert the documents into an inaccessible format. As a result, as things move forward, more of the archived documents will be accessible and will not be in need of conversion. Making new content accessible will improve access for people with disabilities and reduce the amount of content recipients must remediate.

#### A.2.3.2 Exceptions: Preexisting Conventional Electronic Documents

**Eliminate the exception for pre-existing conventional electronic documents** - This exception should be eliminated. The electronic document file formats that are covered by this exception are far too broad and, in general, are made easily accessible. We can think of no reason why

word processing, presentation, and spreadsheet documents should not be required to be accessible. The only documents such an exception could even arguably be justified for would be PDF documents, yet many PDF documents are readily made accessible with limited effort or could be replaced with other formats that are easier to make accessible. In addition, given the department's two-to-three year compliance timeline, this exception will allow entities to accumulate additional documents that are inaccessible and that will nonetheless be of value to people with disabilities. Given the existing defenses for undue burden and fundamental alteration, this newly proposed exception is, at best, unnecessary.

- *Web Accessibility Question 21: Would this “preexisting conventional electronic documents” exception reach content that is not already excepted under the proposed archived web content exception? If so, what kinds of additional content would it reach?*

**This exception will lead to confusion about what information is required to participate in public activities, resulting in unequal access for people with disabilities** - Recipients often host community information sheets, flyers, proposals, and other important updates to their websites using these formats. Recipients build databases to provide public information about programs, such as hospitalization data, as well as to directly carry out those programs. These documents are often living documents and subject to change. Documents are often not archived for a period of several years. Thus, while it is true that the Department has proposed a limitation to safeguard access to activities and programs, there will still be a significant number of documents for which recipients will have to make a determination on a case-by-case basis about whether people with disabilities deserve access to them. This erodes one of the key benefits of the rule - a consistent expectation of accessibility.

This exception could negatively impact disabled people's ability to access crucial data because these documents are important for understanding recipients' programs, activities, and services, but are not “used” to access them. It is also confusing. For example, will a description of a recipient's overall programs and activities that helps a beneficiary or patient make decisions be considered subject to the exception when it is not “used” to “apply for, gain access to, or participate in” any specific program? Recipients may not consistently apply the limitations of this exception.

- *Web Accessibility Question 22: What would the impact of this exception be on people with disabilities? Are there alternatives to this exception that the Department should consider, or additional limitations that should be placed on this exception? How would foreseeable advances in technology affect the need for this exception?*

**People with disabilities must not be required to disclose their disabilities and wait for remediation to access documents intended to be made available to the public** - Recipients may deny that descriptive and informative conventional electronic documents are used to access programs or activities, and therefore, decline to make them accessible. For example, a hospital website is likely to host several years' worth of completed and in progress management plans. They may include information pertinent to planned construction near a



community or planned expansions. This document is not used to apply for, gain access to, or participate in the services, programs, or activities. Yet, this document would be useful to refer to in responding to a public input period or to understand changes in the services provided to a community. Recipients also create an abundance of manuals and materials that are used in employment settings. Adult education programs play an important role in advancing job opportunities for people with disabilities, and having access to the documents needed to learn tools, skills, and programs is very important. For example, if a health practices manual has been produced by the adult learning program, the program may have to make the manual accessible, but if the manual was first produced by, say, a private medical provider for their employees, that entity may consider them to be excluded under this exception. Much public information is highly useful but not necessarily used in the ways envisioned by the limitation.

In addition, according to the NPRM, small recipients will have three additional years to create inaccessible PDFs, presentations, word documents, databases, and spreadsheets that are unusable by people with disabilities. That could result in thousands of new inaccessible documents. For example, many boards and councils must keep meeting materials and information available on their websites for several years without archiving them. These materials may even be required by law to be made public. Because these documents could be interpreted not to be subject to the limitation, they may not need to be made accessible.

However, if a person with a disability wants to respond to a public input period, it would be helpful to review presentation documents that were presented at a prior time, yet they may not be able to do so because the documents remain inaccessible. They must disclose their disability, go through a process to request an accessible format, and wait until they can be made accessible. This exception limits the scope of information and research available to people with disabilities. Like some of the other proposed exceptions, excluding existing documents limits access to public information and data, impedes the work of researchers with disabilities, and could even impede the right “to petition the Government for a redress of grievances.” Given the existing defenses of undue burden and fundamental alteration, the preexisting electronic documents exception seems unnecessary at best and actively harmful at worst.

#### A.2.3.3 Exceptions: Web Content Posted by a Third Party on a Recipient’s Website

- *Web Accessibility Question 23: What types of third-party web content can be found on websites of recipients? How would foreseeable advances in technology affect the need for creating an exception for this content? To what extent is this content posted by the recipients themselves, as opposed to third parties? To what extent do recipients delegate to third parties to post on their behalf? What degree of control do recipients have over content posted by third parties, and what steps can recipients take to make sure this content is accessible?*

**Eliminate the exception for web content posted by a third party, which will undermine disabled people’s access to necessary information** - Recipients ask third parties to post content

on their websites and mobile apps that is instrumental to participation in programs and activities. One significant venue for this content is the social media profiles of recipients because most social networks allow for comments on profile owners' posts by default. In these conversations, individuals and private organizations sometimes weigh in with crucial updates on local events.<sup>60</sup> Social media is particularly conducive to spreading the news of an ongoing emergency in a specific place. A private person's comment on a recipients' Facebook post during an active shooter situation or natural disaster may be more current than the Facebook post itself or local news coverage.<sup>61</sup> Recipients' social media profiles are also spaces for complaining about community conditions, getting advice, and getting organized.<sup>62</sup> Similarly, these spaces are sometimes forums for understanding new programs, health policy, public comments, and public contracts.<sup>63</sup> For these reasons, it is crucial that disabled people have access to third party content posted to recipients' social media platforms.

Off social media, recipients run other digital venues where third parties may post or upload content that is of interest to the general public, including users with disabilities. Here, there is often substantially more delegation to third parties to post content. Providing access to these venues will give people with disabilities more equal opportunity to participate in decision making. For example, many government entities solicit public comments,<sup>64</sup> and these public comment opportunities are often required by law. Third party posts and uploads to these spaces are often available to the public either immediately or after the closure of the comment period, and they are relevant to issues of widespread public concern. In some cases, recipients use apps and websites to solicit real-time feedback during public meetings, and that information is often inaccessible to people with disabilities, especially when presented in dynamic word clouds.<sup>65</sup> These tools may be difficult to use for someone who is blind, has a print-processing disability, or has a cognitive disability. Recipients' websites and online profiles on third-party sites are also sources of information about contracting and procurement, which may present significant financial opportunities.<sup>66</sup>

In addition, schoolteachers and college professors often assign discussion work that requires students to post a video, essay, wiki page, or other work to a class message board to which all students are expected to respond. Students with disabilities cannot fully complete the response portion of the assignment if they cannot access other students' content.

If the exception were eliminated, recipients could take many basic steps to ensure that their content is accessible to all users, including people with disabilities. These include changing settings on some social media profiles to promote accessibility, setting rules for public comment and bid document submission (such as requiring all .pdf documents to be accessible for a contract application to be considered), and prompting users to add alt-text or other features. This would give larger entities, with stronger online presences and more political and economic activity, more work to do to ensure access, but those governmental organizations are also the most resourced and best equipped to take this on. Major social networks have implemented new accessibility features.<sup>67</sup> For this reason, foreseeable technological developments will likely continue to make it easier to implement accessibility features. Removing the exception and relying on the traditional undue burden standard – making states,

cities, and counties responsible for enacting these simple measures – would protect equal access to crucial information without harming recipients that already adjust their social media settings and set rules for processes like public contracting.

- *Web Accessibility Question 24: What would the impact of this exception be on people with disabilities?*

**People with disabilities will lose access to time-sensitive information, educational content, and robust opportunities to participate in public feedback sessions** - The proposed exception would provide many people with disabilities limited and unequal access to crucial information. Recipients maintain knowledge documentation tools for important reasons such as informing the public on community news and events.<sup>68</sup> Allowing recipients that provide public forums and seek public input to avoid responsibility for ensuring this content’s accessibility would deprive many people with disabilities of participation in the full social and political lives of their communities. It may also create confusion about recipients’ other web access obligations. For these reasons, the proposed exception is unnecessary and harmful to disabled people.

The exception may limit disabled residents’ access to discussion of shared grievances and concerns in their communities. Lack of information limits their ability to seek redress for those grievances. This poses barriers to people with disabilities working with their neighbors to address problems at the state and local levels and has the potential to thwart not just the spirit of the Rehabilitation Act and ADA but also their constitutional rights. Similarly, failing to ensure the accessibility of third-party posts will lock disabled users out of certain discussions. This is likely to prevent some people with disabilities from finding out all available information about planning and zoning matters that may pertain to their homes or businesses or about employment, employment training, and contracting opportunities. The exception risks cutting off some routes to economic opportunity for people already struggling to achieve financial success.

Second, individuals are not the only ones generating web content by interacting with recipients online. Other organizations covered by the Rehabilitation Act and ADA also engage in these public conversations.<sup>69</sup> These posts may contain particularly important information for community members, including people with disabilities.<sup>70</sup> Title III entities have strong web access obligations.<sup>71</sup> Presumably, ADA obligations remain in force even when covered businesses and nonprofits post to a recipient’s Facebook group. However, ADA covered entities may be less mindful of their ADA obligations if they are under no pressure from the recipient running the digital venue to make their content accessible. This is true even where the recipient may have gone out of its way to facilitate an interaction by holding a joint event or encouraging third party posts and uploads.

#### A.2.3.4 Exceptions: Third Party Content Linked from a Recipient’s Website Section

**Eliminate the exception for linked third-party web content** - This exception along with the exception for third-party content posted on recipients’ websites and apps creates confusion

about the extent to which recipients' third-party vendors, contractors, and partners must participate in making recipients' services, programs, and activities accessible. Further, it absolves entities of their responsibility to make sure that they are providing accessible information to the public. Given the likely confusion this exception will create and the limited number of links that could definitively be identified as not being used "to participate in or benefit from the recipient's programs or activities," this exception should be eliminated.

- *Web Accessibility Questions 25/26: Do recipients link to third-party web content to allow members of the public to participate in or benefit from the entities' programs or activities? What would the impact of this exception be on people with disabilities?*

**Third parties must share some of the responsibility for making their content accessible, and recipients must have the responsibility to select accessible content that is linked on their websites or apps** - Linked third party web content should be fully accessible regardless of whether it is used to facilitate a recipient's program or activity. Significant and important information is published via third party linked content, and these providers are often themselves ADA covered entities or have nondiscrimination obligations under the Rehabilitation Act. In addition, many third-party content providers benefit financially from such linkage on recipients' sites and apps.

Information linked to on recipients' websites is typically provided as part of the entity's public information activities or is necessary for taking part in other activities. For example, a public health department may provide up to date information about a sudden or ongoing shortage of a particular medication (common for people with epilepsy and other medical conditions like diabetes and for vaccine distribution) and identify which pharmacies still have a supply by linking to ADA Title III covered pharmacy websites. Likewise, information on access to specialized healthcare services such as family planning not provided directly as a program or activity of a recipient is often provided via linked content. It is vital that this information be accessible to all, but this exception creates uncertainty about whether the link is providing information as a service of the recipient or another entity. We believe that websites are a program in and of themselves, and this exception undermines recipients' obligation to provide accessible information.

To the extent that a recipient does not have control over the linked content to remediate accessibility barriers, the entity can still choose not to link to information that discriminates against people with disabilities. We are also concerned that this exception will undermine recipients' attempts to bring their vendors and partners into compliance with the law. Recipients need to be able to clearly point to the regulation to hold those vendors accountable for creating accessible web and mobile app content. We note that a web and mobile app accessibility regulation under Title III of the ADA would clarify that much of the information to which recipients link must be made accessible. All in all, this exception should be eliminated.

#### A.2.3.5 Exceptions: Password-Protected Class or Course Content of Educational Institutions

The proposed exceptions for content used by educational institutions are especially egregious. We urge the Department to eliminate these exceptions and ensure that students with disabilities have equal access to their education.

- *Web Accessibility Question 28: Are there particular issues relating to the accessibility of digital books and textbooks that the Department should consider in finalizing this rule? Are there particular issues that the Department should consider regarding the impact of this rule on libraries?*

**Libraries must expend time and effort to provide accessible books to patrons because publishers frequently deliver inaccessible content** - Digital books, materials, and technologies should conform to the standards for accessibility under WCAG 2.2. While more flexible than print, if accessibility is not considered from the start, digital materials can present many of the same barriers as their print-based counterparts. And the technology that delivers those materials, from e-reader devices to learning management systems, must work with accessible digital materials, so that individuals with disabilities have the same experience as those who do not have disabilities.

Libraries and schools are also heavily dependent on publishers to deliver accessible book formats. As such, the Department should clarify that while the school or library may be ultimately responsible, the third-party publisher plays a significant role in delivering accessible digital books and textbooks. If all libraries and schools required publishers to deliver accessible versions of their books and could point to this regulation, it would reduce the work required by those libraries to remediate books and reduce the amount of time that patrons with disabilities wait for access.

#### A.2.3.6 Exceptions: Postsecondary Institutions: Password-Protected Web Content

- *Web Accessibility Question 30: What would the impact of this exception be on people with disabilities?*

**Eliminate the exception for postsecondary institutions' password-protected course content. Inaccessible content has serious implications for students' on-time completion of their chosen course of study** - This exception must be eliminated to protect the ability of people with disabilities to attend and graduate from college. In one study during the pandemic, 57 blind or low vision higher education students reported dropping a class, taking an incomplete, leaving their program, or having to file an official complaint because of inaccessibility in hybrid or online courses.<sup>72</sup> In addition, the harms caused by inaccessible educational platforms and instructional materials (delivered both by websites and mobile apps) are sharply depicted by the *Payan v. Los Angeles Community College District* litigation, Case No. No. 2:17-cv-01697 (C.D. Cal.). For years, blind students Roy Payan and Portia Mason were excluded from education because of inaccessible classroom materials, textbooks, websites, and educational applications (like MyMathLab and Etudes). They could not keep up with reading assignments, follow along with in-class PowerPoints, complete classroom activities, or participate in online classroom

discussions. They could not independently enroll in classes or use library databases. Access was so delayed that they had to choose between dropping classes or accepting lower grades. A jury found that the exclusions caused Mr. Payan more than \$200,000 in damages.

It does not make sense for the Department to place an exception on requirements for accessibility as it relates to password protected course content when colleges and universities are already required to make *all* course materials accessible under the ADA,<sup>73</sup> and in fact, many are already striving to comply. The Department must promote a policy consistent with existing Federal policy, including the May 19, 2023, Dear Colleague Letter on Online Accessibility<sup>74</sup> that supports people with disabilities and also clarifies for all recipients that they must develop coordinated accessible and usable online systems that support interoperability with assistive technology. To require accessibility only upon gaining knowledge of a student with a disability registering for a course sets current law and best practice back, and it harms access to important course content for a person with a disability attending a post-secondary institution. Among its flaws to ensure accessibility for all individuals with disabilities, the exception does not effectively anticipate late registrants to courses, who may add or drop courses as allowed under an institution's registration policy. In this case, a student would have to wait days or even weeks before accessing course content. The consequences are even more severe for students taking a January or summer term course in which a 5-day delay may be a third of the entire course.

Additionally, federally funded technical assistance resources exist for college/university use and include actionable language for developing a coordinated system that leads to the timely provision of accessible materials and technologies in higher education settings for all students who need them.<sup>75</sup> The regulations must clarify that all course content must be *designed and developed* to be accessible, usable, and interoperable with assistive technology whether from inception (e.g., new and teacher created) or from procurement. Course materials that exist within a password protected area are no exception.

Recipients are also beneficiaries of accessible design: Creating a new document that is accessible will prevent entities from having to recreate the document. Frequently, the same document will have to be remediated multiple times as the inaccessible document is used in multiple courses or at different institutions. It is unconscionable that in 2023, the Department expects any person with a disability to 'wait' for their content and to overcome a delay when other students are not required to do so. Equal opportunity begins with equal access, and in this context, there is every capability and expectation that an institution receiving public funds must not delay compliance with the law.

#### A.2.3.7 Exceptions: Elementary and Secondary Schools: Password Protected Web Content

**Eliminate the exception for elementary and secondary schools' password-protected course content** - This exception must be eliminated to protect students' access to their education. Most web and app content is provided through some kind of authenticated system as it facilitates student privacy, cybersecurity, assigning grades to individual students, saving student

progress, and the organization of class content. While we are grateful that the Department has considered the needs of parents with disabilities in crafting the exception, parents and students with disabilities would be better served by creating a consistent expectation of accessible course and class content.

This exception ignores and undermines requirements of the Individuals with Disabilities Education Act (IDEA) which mandate equitable access to learning opportunities for students with disabilities, including equal access to printed materials, digital materials, and technologies<sup>76</sup>. Specifically, the exception conflicts with the U.S. Department of Education recommendations to States and school districts regarding the best ways to exemplify conditions and services for creating and sustaining a statewide, high-quality accessible, educational materials (AEM) provision system that is also designed to meet statutory requirements under the IDEA<sup>77</sup> and to assure students have access to the requisite assistive technology<sup>78</sup> to access AEM. If the exception remains, virtually every student with a relevant disability would be discriminated against.

- *Web Accessibility Question 39: What would the impact of this exception be on people with disabilities?*

**This exception would continue to normalize the exclusion of people with disabilities, put students behind in their classes, and create additional work for teachers** - Recently, the American Foundation for the Blind conducted research into educational barriers faced by blind and low-vision students during the COVID-19 pandemic. The research documented the discriminatory impact of inaccessible digital equipment, platforms, programs, and instructional materials. One of the most significant barriers was the use of websites and applications – such as those used for student learning and curriculum, classroom management, file creation, and communication – that were inaccessible to blind or low vision students and family members. These are typically accessed via a password protected portal or learning management system. Nearly 60 percent of educators surveyed reported that their blind and low vision students could not access at least one digital classroom tool or program; 35 percent reported that their students could not access at least two tools.<sup>79</sup> Family members surveyed reported their children were expected to use an average of 4.9 different tools or programs but, on average, 2.7 tools or programs were inaccessible.

During hybrid and online learning, preschool and elementary school students were unable to complete required assignments and often needed continuous support from a family member; this negatively affected the family member's ability to work. Unable to participate and access lessons like their peers, blind and low vision students felt frustrated, discouraged, and excluded. Educators had to invest additional resources to create alternative lessons for their students with disabilities or, in the absence of an alternative, simply exempted the child from lessons delivered via inaccessible digital platforms.<sup>80</sup>

One family member wrote:

“My biggest frustration is overall accessibility. Example, the class is assigned an online science simulation on creating circuits that is produced by a curriculum company. The science simulation is visual with no auditory information and the only way to connect the pieces is by using finger gestures. My child can’t see the parts so can’t do the assignment. The common answer for this situation is to exempt my child because it is too visual. Why? [...] Why does my child not have the opportunity to learn ideas and concepts because companies don’t make things accessible, schools buy those inaccessible programs and then don’t provide an alternative way to learn the same information?”<sup>81</sup>

As the Department knows, websites and apps are ubiquitous in education, both at the K-12 and postsecondary levels. Most K-12 schools and universities use LMS<sup>82</sup> - only 6 percent of K-12 educators said their district doesn’t use an LMS.<sup>83</sup> Unfortunately, too often developers and publishers do not create accessible platforms and educational products, creating barriers for students with disabilities as schools have moved to online learning spaces in 2020 and beyond.<sup>84</sup> Importantly, tools do exist (and have existed for some time) to support the accessible design of the learning platforms and digital materials.<sup>85</sup> Given the ever growing trend and expanded need to place student course content onto the web for all students, including this exception sets us back, prevents a planning and design process that ensures technology and digital materials are ‘born accessible’, and would be extremely detrimental to K-12 students with disabilities.

Finally, the exception adds an onerous burden to the families of students with disabilities. Because federal law requires students with disabilities to exhaust administrative remedies under the IDEA before pursuing ADA enforcement, there will be no way for students to demand access in a timely way to inaccessible course materials.

Given these pervasive and continuing barriers for students with disabilities, we urge the DOJ to adopt a rule that ensures that all technology used in the classroom to deliver instruction be accessible to all individuals with disabilities. This should include kiosks, websites, and applications; third-party websites or apps used for class content; and any form of information and communication technology, including Virtual Reality (VR).

#### A.2.3.8 Exceptions: Individualized Password-Protected Documents

Eliminate the exception for individualized, password-protected documents - In accordance with current law, many of the documents covered by this exception are already made accessible by recipients. The introduction of this exception in the proposed rule would encourage those same recipients to utilize this easy way out of making the individualized documents accessible. Thus, this exception should be eliminated.

- *Web Accessibility Question 47/49: What kinds of individualized, conventional electronic documents do recipients make available and how are they made available? What would the impact of this exception be on people with disabilities?*



**There is a huge variety in the types of individualized, password-protected documents and many are time-sensitive** - Medical providers make test results, clinical summaries, and post-operative care instructions available as conventional electronic documents, especially PDFs, through online portals and electronic health record apps. Facilities provide records of current and past bills online that can be referred to when questions arise. A human services provider may offer an online portal or app for accessing applications and determination letters. Some of these systems may also use html formats, but many others provide conventional electronic documents such as PDFs. Doing so makes the document sharable and printable, so that, for example, they can be used to submit insurance claims or to access services in person. It would not be difficult to make the vast majority of these documents accessible from the beginning as a matter of course. Pursuant to current law, many of these documents are already accessible, so people with disabilities can access them using assistive technology. For those that are not accessible, people with disabilities must rely on companions or strangers to read their documents, attempt to request accessible formats, or pursue legal action. Not infrequently, people with disabilities simply cannot access documents, including ones that describe follow up care instructions. It can be time consuming and frustrating to constantly request that available materials be made accessible on a recurring basis. A patient who has just had surgery may not have the wherewithal or energy to make a special request.

This exception would be a step backward for people with disabilities. Just when entities are beginning to make progress and bills and other information are finally available in formats that are easily made accessible, this exception would reverse course and allow those formats to remain inaccessible. People with disabilities would continue to have difficulty paying bills, receiving communications from their doctors, reviewing and using school transcripts, reading job offer letters or notices related to a contract, accessing medical records, and more. It would delay access to information, increase the likelihood of missing a payment deadline, and increase frustration and effort. It would also disincentivize entities from prioritizing accessibility when building online portals now and in the future. Furthermore, setting a consistent expectation of accessibility is necessary to ensure that vendors provide accessible automated document generation systems to recipients, reducing the work of remediating each individual document.

- *Web Accessibility Question 48: Do recipients have an adequate system for receiving notification that an individual with a disability requires access to an individualized, password-protected conventional electronic document? What kinds of burdens do these notification systems place on individuals with disabilities and how easy are these systems to access? Should the Department consider requiring a particular system for notification or a particular process or timeline that recipients must follow when they are on notice that an individual with a disability requires access to such a document?*

**The time entities would spend on building a notification process would be better spent on making the documents accessible from the start** - Recipients generally provide no clear means for a resident to notify them of the need for accessible documents, either on the login pages of

their password-protected portals or within the system. They may provide a webmaster or contact person from whom to request accommodations, but this contact information is not always easy to find. In other cases, an individual with a disability must call for assistance. Thus, this exception is likely to increase the time, effort, and frustration required to use electronic health records and other online portals.

If this exception were to remain in place, it is essential that there be a clearly accessible mechanism, on the front page of the portal and throughout the online system, to request accessible versions of the provided documents. Moreover, because these are often bills and other time-sensitive matters, it is essential that recipients be required to provide accessible format documents quickly, and well in advance of any deadline for the documents. For post-operative instructions, accessibility must be available on the same day, because a person with a print disability generally cannot access the print documents they received in person. In addition, the person with a disability is likely to miss a payment deadline at least once waiting for an accessible document. Finally, once a request for accommodations is made, the recipient must provide a means such that no further individualized requests from that person with a disability are required and all future notices or documents sent to that individual are automatically delivered in an accessible format. This is also important when people with disabilities need to see multiple providers within a single system as with affiliated hospitals, doctors, and laboratories. The Social Security Administration, Internal Revenue Services and several state benefits agencies have demonstrated examples of such an opt-in approach to default accessible formats. It would be far better, however, for all documents to be accessible to prevent the possibility of unexpected documents requiring an individual to pursue the process anew.

#### ***A.2.4 Measuring Compliance***

**The Department should pair the latest WCAG standard with a functional definition of accessibility.** The Department asks a series of questions about measuring compliance and enforcement of the proposed rule in Web Accessibility Questions 52 to 61. We encourage the department to consider adopting a functional definition of accessibility in addition to setting a minimum standard of accessibility. A website or mobile app should enable individuals with disabilities to access the same information as, to engage in the same interactions as, to communicate and to be understood as effectively as, and to enjoy the same services as are offered to, other individuals with the same privacy, same independence, and same ease of use as individuals without disabilities. WCAG 2.2, Level AA, is our recommended clear and consistent standard for achieving that level of access. However, we acknowledge that there may be circumstances, as the department notes, in which nonconformance with the technical standards does not erode access, privacy, independence, or ease of use. An example may be the absence of alt-text on visual elements that convey no additional meaning and do not contribute to the structure of a page. While recipients should be expected to fix such issues, they are not priorities for enforcement. At the same time, it is also possible that conformance with WCAG 2.2, Level AA, could still result in a lack of equivalent access to people with disabilities, such as with the use of certain authentication measures. As such, we suggest that

the Department's questions about an alternative compliance regime are best addressed by adopting a functional definition of disability that complements the technical standard rather than any of the other proposed schemes: e.g., requiring a percentage of conformance or demonstrating organizational maturity.

### **A.3 Subpart J - Accessible Medical Equipment**

CCD strongly supports HHS's efforts to apply specific requirements for accessible medical equipment. Inaccessible medical diagnostic equipment (MDE) effectively excludes certain people with disabilities from accessing routine examinations and specialized medical care. Due to inaccessible equipment, people with disabilities may be excluded from certain types of exams or treatment, may be delayed in receiving medical treatment because of an inability to access medical care, or receive subpar medical examinations. These issues, and more, can result in undetected medical conditions, exacerbation of their known disabilities, and the development of secondary condition<sup>86</sup> We agree that regulated entities, physicians, and other healthcare professionals would benefit from specific technical guidance and training on how to fulfill their obligations and make their services accessible. However, some of the proposed requirements do not fully ensure people with disabilities have equal opportunities to access medical services.

#### ***A.3.1 Access Board MDE Standards and Low-Transfer Height***

The U.S. Access Board issued the Standards for Accessible Medical Diagnostic Equipment (MDE Standards) in 2017; however, these standards remain unenforceable. CCD supports HHS' proposal to adopt and incorporate the technical requirements set forth in the MDE Standards. But the Access Board has not yet issued a final rule on MDE low transfer heights. In 2017, the Board concluded more information was needed. After two research studies, in May 2023, the Board issued an NPRM proposing a 17-inch low transfer height. The reports strongly support a 17-inch low transfer height to ensure access and minimize the risk for patients, providers, and staff that manually transfer wheelchair users. A 17-inch low transfer height provides the greatest number of wheelchair users the opportunity to transfer independently.<sup>87</sup> In anticipation that the Access Board's 17-inch rule will imminently be finalized, we recommend HHS adopt a 17-inch requirement in the Section 504 final rule. The Access Board NPRM received strong support from people with disabilities and advocates concerning the transfer height. Its inclusion within the final 504 rule will give manufacturers a strong incentive to produce compliant equipment that can be acquired by recipients and avoid further delaying equal opportunity to medical care for people with mobility disabilities.

#### ***A.3.2 Requirements for medical diagnostic equipment (§ 84.91)***

CCD agrees that a recipient cannot require a patient with a disability to bring a companion to provide reasonable assistance. As the DOJ also concluded, requiring a patient to bring a companion for transfer or other assistance affords treatment that is not equal to that afforded to people without disabilities.<sup>88</sup>

### ***A.3.3 Newly purchased, leased, or otherwise acquired medical diagnostic equipment (§ 84.92)***

CCD supports HHS' proposal to require all MDE a recipient purchases, leases, or otherwise acquires after the rule's effective date to be accessible, which aligns with the ADA's scoping requirements for new construction and alterations of buildings.

### ***A.3.4 Requirements for newly purchased, leased, or otherwise acquired medical diagnostic equipment (§ 84.92(a))***

CCD recommends HHS clarify that any lease renewal is considered a "new" lease, and the equipment must meet the scoping requirements for new equipment. Without this clarification, recipients may renew leases on existing equipment, further delaying their obligation to acquire accessible equipment.

- *MDE Question 1: The Department seeks public comment on whether and how to apply the existing scoping requirements for patient or resident sleeping rooms or parking spaces in certain medical facilities to MDE; and on whether there are meaningful differences between patient or resident sleeping rooms, accessible parking, and MDE that the Department should consider when finalizing the scoping requirements.*

The proposed scoping requirements do not ensure equal access to medical services for people with disabilities. CCD urges HHS remove any distinction in scoping requirements based on the provider, clinic, or department's specialty. People with disabilities must have an equal opportunity to access all medical specialties, even if the specialty does not, on its face, treat conditions that affect mobility. Moreover, the practical application of determining which specialties treat conditions that affect mobility is unworkable. People with disabilities are excluded from various types of medical care due to inaccessible MDE. Due to accessibility barriers, people with disabilities are unable to access urological, OB/GYN, podiatry, optometry, dental, and other essential medical care. Although these specialties are not focused on addressing mobility conditions, access to these services is critical and potentially lifesaving.

Instead, the Department should require all MDE purchased, leased, or acquired after the rule's effective date to be accessible. Accessible MDE is not comparable to parking spaces. If accessible equipment is compared to parking spaces, people with disabilities inevitably receive unequal opportunity to access services and benefits. Requiring all medical equipment to be accessible offers equal opportunities for individuals with disabilities as those without disabilities.

Furthermore, HHS' focus on time-limited use of MDE is misguided. Although multiple patients with disabilities may theoretically use some accessible equipment in the same day, their appointment scheduling options are greatly reduced compared to those without disabilities resulting in unequal access. When individuals with disabilities must schedule an appointment only when accessible equipment is available, they face increased burdens, especially when accessible transportation, like paratransit, may be limited by time and geographical boundaries. This may exclude an individual with a disability from receiving care. In addition, some equipment,

like dental chairs, may be occupied for a greater length of time than a weight scale. Moreover, sometimes the need for accessible equipment cannot be easily identified in advance of a visit. Many people with limited mobility, especially those with newly acquired disabilities, may not be aware they have to notify their provider in advance that they require accessible equipment, but nonetheless will require it when they arrive for an appointment. If the only exam room with accessible equipment is in use, that person could be required to reschedule their visit, thus care will be inequitable. If all exam rooms are equipped with accessible equipment no such scheduling problem will arise.

Furthermore, a 10 percent requirement will inevitably fail to offer equal medical services for the current and future number of Americans with mobility disabilities. As of 2023, 12.1 percent of U.S. adults have a mobility disability.<sup>89</sup> This number does not include children with disabilities. In addition, the U.S. population is aging. The number of older adults in the U.S. are growing in number and expected to outnumber children by 2034.<sup>90</sup> The United States has added 2.7 million more adults with disabilities in the past two years.<sup>91</sup> This is a significant increase in contrast to previous years. Older adults have higher rates of ambulatory disabilities,<sup>92</sup> and as the population ages, the number who use mobility assistive devices will increase.<sup>93</sup> HHS can assume that the number of Americans with mobility disabilities will continue to increase. A 10 percent requirement for any specialty does, and will continue, to exclude individuals with disabilities from accessing all medical specialties.

HHS should model Section 504 regulations on ADA Title II transportation accessibility requirements.<sup>94</sup> Title II requires all newly purchased and leased vehicles be readily accessible to and usable by people with disabilities (the replacement rule).<sup>95</sup> Despite transportation agencies urging a lesser percentage due to the cost of manufacturing and acquiring accessible vehicles, disability rights advocates rightly argued that only with 100 percent accessible transportation can people with disabilities have equal access. After the requirement was issued, transportation providers did not incur the higher upfront costs expected because they only needed to acquire accessible vehicles as older vehicles were replaced. In addition, recent research found the benefits of investments in accessible transportation and infrastructure outweighed the costs.<sup>96</sup> CCD urges HHS to use a comparable replacement rule and require all newly purchased, leased, or acquired MDE to be accessible after the rule's effective date. Only with this approach will individuals with disabilities have equal opportunities to access medical services.

- *MDE Question 2: The Department seeks public comment on whether different scoping requirements should apply to different types of MDE, and if so, what scoping requirements should apply to what types of MDE.*

As outlined in our response to question one, CCD recommends HHS apply the same requirements to all MDE. Only with 100 percent accessible equipment can Section 504's requirement for equal opportunity be attained.

- *MDE Question 3: Because more patients with mobility disabilities may need accessible MDE than need accessible parking, the Department seeks public comment on whether the*

*Department's suggested scoping requirement of 20 percent is sufficient to meet the needs of persons with disabilities.*

As outlined in our response to question one, CCD recommends HHS apply the same requirements to all MDE. Only with 100 percent accessible equipment can Section 504's requirement for equal opportunity be attained.

- *MDE Question 4: The Department seeks public comment on any burdens that this proposed requirement or a higher scoping requirement might impose on recipients.*

The consideration of financial costs of compliance is unwarranted. When considering additional costs for wheelchair-accessible restrooms, the DOJ concluded, "the additional benefits that persons with disabilities will derive from greater safety, enhanced independence, and the avoidance of stigma and humiliation—benefits that the Department's economic model could not put in monetary terms—are, in the Department's experience and considered judgment, likely to be quite high."<sup>97</sup> With exceptions for undue financial burdens, recipients maintain a limited safe haven for situations when financial resources are legitimately unavailable to meet the requirements.

Furthermore, if all MDE is accessible, it will reduce administrative burdens on recipients. When accessible equipment is limited, staff may need to identify the location of accessible equipment and ensure the equipment is available during the appointment time. Accessible medical equipment will increase efficiencies for staff in that everyone will find greater ease in using it regardless of age, mobility limitations, and other general population limitations. These burdens will be eliminated if accessible equipment is available in all hospitals, clinics, and departments. Per CMS requirements, covered hospitals must maintain a list of equipment inventories and documentation of their maintenance activities.<sup>98</sup> For administrative and practical purposes, HHS should also require recipients to maintain a list of accessible equipment in their inventories and systems until all equipment is accessible.

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

As recognized by HHS, full dispersion across every department, clinic, and specialty would be difficult to determine whether scoping requirements have been satisfied. Without requiring all newly purchased, leased, or acquired equipment to be accessible, it is administratively impracticable for a recipient and HHS to identify whether the recipient is in compliance. Scoping percentages are not an appropriate way for HHS to ensure equal opportunity to health programs and services. Using the replacement approach, requiring all newly purchased, leased, or acquired MDE to be accessible provides an easy test to determine compliance.

Until a recipient reaches 100 percent accessible equipment, dispersion requirements must still be identified. If this approach is adopted, HHS should clarify that the dispersion requirements

apply only in the interim. Our following comments on dispersion requirements assume they will only be in place until complete accessibility is achieved. CCD again urges HHS to not distinguish scoping requirements based on the specialty of the provider, clinic, or department.

All types of MDE must be accessible for individuals with disabilities, without requiring separate treatment. While a recipient is in the process of transitioning towards accessible equipment, all booking systems must indicate where and when accessible equipment is available. If accessible equipment must be shared by multiple departments, the recipient must ensure the dispersion does not result in unequal treatment, such as a patient needing to go to one floor, building, or clinic to be weighed and another to receive care or treatment. This requirement should be specifically examined if a recipient's services are offered in unattached buildings or when clinics or departments are located in buildings not immediately adjacent to the building where the patient needs services.

Some equipment may be used by different specialties, such as an accessible weight scale; however, other equipment, including different types of tables and chairs may be designed for specific services. For example, a medical chair used by a podiatrist may likely not be used for OB/GYN services. To comply with Section 504, recipients must ensure equal access to *all* programs and services. Recipients must treat patients with disabilities equal to all other patients. If it is necessary during the transition period that accommodations are needed, such as accessible transportation to other locations, these must be offered and paid for by the recipient.<sup>99</sup>

- *MDE Question 6: The Department seeks public comment on whether additional requirements should be added to ensure dispersion (e.g., requiring at least one accessible exam table and scale in each department, clinic, or specialty; requiring each department, clinic and specialty to have a certain percentage of accessible MDE).*

Removing the scoping requirements based on specialty eases the burden on HHS and the recipient to determine where additional accessible equipment is required. In addition, as the ADA requires all new construction to meet accessibility requirements, recipients must meet comparable requirements. The purpose of the ADA's new construction and alteration requirements was to move towards equitable and integrated access for people with disabilities in everyday life. HHS must use the same type of approach for medical services, equal and integrated access. CCD urges HHS to remove any distinct percentages based on specialty. The ADA outlines dispersion requirements for equal access and opportunities. The dispersion requirements outlined below only apply until all equipment is accessible.

For accessible exam tables or chairs, at least one for each specialty must be required until all equipment is accessible. Allowing departments to share accessible equipment may result in unequal opportunities to receive program services. The patient may be forced to traverse to one department to be weighed on an accessible scale then traverse to a different department for the services needed, unlike those without disabilities who can be weighed and receive care in the same department. In addition, various examination tables or chairs may not be used by a different specialty for treatment. At minimum, at least one accessible exam table and weight

scale must be located in an adjacent department on the same floor.

CCD's proposed requirements will also reduce burdens on the recipient. It will reduce the administrative burden placed on staff tasked with locating, tracking, or obtaining accessible MDE for use during an appointment; reduce the amount of time spent attempting to locate accessible equipment in another department; reduce the risk of the unavailability of accessible equipment due to potential double booking by a different department; reduce the burden on the patient to travel to another floor, unattached building, or building not immediately adjacent to where services are rendered; reduce the wait time for patients and staff to access the equipment; reduce disparate and separate treatment of patients with disabilities; and ensure patients with disabilities do not encounter barriers to receiving care.

Further, recipients must ensure that the location of the equipment protects the privacy of the patient with a disability during the equipment's use to the same extent that use of non-accessible equipment protects the privacy of non-disabled patients. For example, if a non-accessible weight scale is located in a private hallway in a clinic, an accessible weight scale may not be located in the public waiting room, even if this appears to facilitate the shared use of equipment by adjacent departments. This would result in unequal treatment because a non-disabled patient's privacy would be protected while a disabled patient's privacy would be compromised by the act of being weighed in front of other patients and family members. Similarly, an accessible exam table must be utilized in a private location that is comparable to exam rooms without accessible equipment whether or not it is shared between departments.

- *MDE Question 7: The Department seeks information regarding the extent to which accessible MDE can be moved or otherwise shared between clinics or departments.*

Except for some types of accessible exam tables, many types of accessible MDE are not readily moveable. For example, MRI, PET, and CT machines are installed into a stationary physical space. In addition, not all medical chairs or even powered examination tables can be readily moved or sometimes be moved at all. Especially due to the inability to move many types of equipment, HHS should require each department to have accessible equipment, or equipment that can provide a thorough examination or treatment in each department, or at least have accessible equipment that can be shared and still provide a thorough exam located in an adjacent department on the same floor.

Even for the limited number of moveable MDE, like wheeled accessible exam tables or moveable accessible weight scales, the recipient would need to use a specialized system for locating the accessible equipment, booking the patient's appointment at the exact time the accessible equipment is available, and ensuring the shared department maintained the equipment in working order. Staff would still then be tasked with locating and moving the accessible equipment or transporting the patient to the department where the accessible equipment is located. For all situations, the recipient faces higher burdens than simply acquiring accessible equipment.



***A.3.5 The burdens that the rule's proposed approach to dispersion or additional dispersion requirements may impose on recipients***

As previously discussed, the dispersion requirements outlined by HHS will actually increase the burden on the recipient.

***A.3.6 The burdens that the rule's proposed approach to dispersion may impose on people with disabilities (e.g., increased wait times if accessible MDE needs to be located and moved, embarrassment, frustration, or impairment of treatment that may result if a patient must go to a different part of a hospital or clinic to use accessible MDE)***

When only a limited number of accessible equipment is available, patients experience decreased options for appointment times compared to patients without disabilities. If the patient must be transported to a separate department or clinic, they are disparately treated when compared to patients without disabilities. These increased wait times and transportation barriers cost people with disabilities precious time that should be spent otherwise on raising families, employment, educational pursuits, community engagement, or simply enjoying life. Additionally, they can cause increased stress through embarrassment, frustration, and the continuing feeling of disparate treatment than patients without disabilities. If the clinic or department fails to have any accessible equipment at all, the patient may need to travel further distances, if there are even options for accessible transportation to the new location. If the recipient does not offer accessible transportation at no cost, the patient will incur additional travel expenses. Furthermore, if the patient is required to pay for two separate visits because of the need to go to a different department or clinic, they may face substantial financial burdens. If recipients are permitted to only have a certain number of accessible equipment, patients with disabilities may ultimately be fully excluded from accessing medical services. If the recipient fails to have even a single type of accessible equipment, the patient may be denied this service.

***A.3.7 Requirements for examination tables and weight scales. (84.92(c))***

- *MDE Question 8: The Department seeks public comment on the potential impact of the requirement of paragraph (c) on people with disabilities and recipients, including the impact on the availability of accessible MDE for purchase and lease.*

Accessible weight scales are readily available with no substantial cost to the recipient. Other types of accessible equipment may pose burdens based on the low-transfer height standard, the type of equipment, whether any equipment that meet standards are currently on the market, requirements on the manufacturers before they can market specific equipment, and the size of the new accessible equipment. These burdens are outlined below in response to the date certain for compliance. HHS must also consider the procurement process for certain MDE. But HHS should balance these against the potential factors that reduce the recipient's burden for compliance, such as leasing equipment, the typical length of leases, whether a lease can be terminated prior to the end of the lease period, and whether refurbished equipment can be purchased that meets the accessibility standards.

- *MDE Question 9: The Department seeks public comment on whether two years would be an appropriate amount of time for the requirements of paragraph (c); and if two years would not be an appropriate amount of time, what the appropriate amount of time would be.*

For accessible weight scales, we believe one year is a more appropriate time frame for recipients to comply with the requirements of paragraph (c). There are a sufficient number of accessible weight scales on the market and available at varying costs. Recipients may also purchase or lease refurbished weight scales. In addition, accessible weight scales need minimal staff training to ensure appropriate and safe use. Thus, one year is sufficient for weight scales.

For accessible tables, without a set low transfer height requirement, it cannot be determined whether a sufficient supply is available. For this reason, HHS must promulgate a 17-inch requirement so manufacturers can further market equipment to meet this standard. After a 17-inch requirement is issued, a two-year compliance date is appropriate. Once this requirement is set, manufacturers must have sufficient time to design, manufacture, and accessible MDE, market examination tables, and recipients must be given an appropriate, but not delayed, amount of time to procure accessible equipment.

Acquisition timeline requirements must include more than just examination tables and weight scales. The MDE Standards also explicitly cover mammography equipment, x-ray machines, examination chairs, and other radiological and imaging equipment. CCD strongly recommends HHS include appropriate acquisition timeframes for other types of accessible equipment.

For some equipment, there are no accessible options on the market. A reasonable, but not delayed, timeframe must be required depending on the type of equipment, such as whether the equipment is an FDA Class I device, which will apply to most equipment, or a higher class that requires FDA 501(k) notification or pre-market approval. In addition, some recipients, especially larger hospitals, must undergo a lengthy procurement process to acquire new equipment. For a majority of Class I medical equipment, or equipment that meets the HHS standards in the final rule, a two-year timeline is reasonable. If no accessible equipment exists, an appropriate, but not delayed, amount of time for acquisition should be required. If the recipient is unable to comply with the initial date certain due to manufacturing or procedural matters, the recipient has the affirmative undue burden defense. However, the recipient cannot continue to use the undue burden defense once the equipment is available and can be acquired.

### ***A.3.8 Requirements for examination tables and weight scales - recipients with fewer than fifteen employees (§ 84.92(c))***

Section 84.22(c) proposes a safe harbor for small health, welfare, and other social providers with fewer than fifteen employees. However, CCD urges HHS to remove any safe harbor, or at the very least consider ways to substantially reduce its scope. The “15 or fewer employees” criteria dates back to the original 504 regulations developed in 1977. The past 45 years have seen great changes

in the structuring and independence of healthcare offices. A 2021 analysis of physician ownership and practice structures found, for the first time, a “majority of patient care physicians worked outside of physician-owned medical practices.”<sup>100</sup> This is a matter of both ownership and employment choices, particularly those made by more recent graduates. Over 50 percent of physicians continue to work in practices that have 10 or fewer doctors, but over 30 percent of all patient-care physicians worked in practices at least partially owned by a hospital or health system. The analysis also found physicians moving toward employment status and away from self-employment status, and an ongoing trend toward larger practice size.

Certainly, any practice that is partially owned by a larger entity, and any physician who chooses to employ other physicians rather than enter a profit and risk-sharing arrangement should be financially capable of acquiring an exam table and weight scale. Similarly, specialist provider(s) who maintain a small practice which could fall under the “fifteen or under employees” rule should be responsible for ensuring they have accessible equipment that is specific to their area of practice. People with disabilities should face lower, not higher barriers to obtaining specialty care, including in those lucrative specialty areas where a small physician-owned practice is most likely. We note also that any recipient, including a small recipient, maintains an affirmative defense that compliance would result in a fundamental alteration or undue burden. However, recipients must consider all possible resources that can meet the patient’s needs prior to claiming the accessible service results in a fundamental alteration or undue burden. The bar for a fundamental alteration or undue burden defense must be high.

#### ***A.3.9 Equivalent Facilitation (§ 84.92(d))***

CCD agrees that in all cases where an alternative is necessary, the recipient must provide a program or service that is equivalent, or provides greater accessibility and usability, than the MDE Standards. The provider and staff must also engage in an interactive process with the patient, which includes giving due consideration to the patient’s preference, and conduct an individualized assessment of the patient’s needs.<sup>101</sup> Qualified staff must also explain the alternative in plain language and attain the patient’s consent to use the alternative option.

#### ***A.3.10 Fundamental Alteration and Undue Burden (§ 84.92(e))***

We agree HHS should adopt the proposed Section 84.88, which outlines fundamental alteration and undue burden defenses in accordance with the ADA. The bar for such defenses must be high, and the recipient must still allow individuals with disabilities to participate in and benefit from the services.

#### ***A.3.11 Diagnostically required structural or operational characteristics (§ 84.92(f))***

For equipment, such as MRI or PET scans, that cannot be made accessible due to structural or operational characteristics, recipients must consider all possibilities to ensure the dignity and independence of the patient. MRI machines, for example, use high-powered magnets, and certain metals (such as metal in wheelchairs and other assistive equipment), can be a hazard so

appropriate precautions and accommodations must be made for individuals with disabilities. In addition, if lifting a patient provides the greatest accessibility, the recipient must ensure staff is qualified and properly trained to reduce the risk of injury to the patient or staff. For any patient lifts, CCD strongly urges HHS require the recipient use a mechanical patient lift to facilitate transfer. Staff must ensure the mechanical lift is available at the time of the patient's appointment. Such equipment must be properly maintained in working order and staff must be trained on how to safely use the equipment to protect the safety of both the patient and staff. In any case where an alternative option is necessary, the provider and staff must engage in an interactive process with the patient, which includes giving due consideration to the patient's preference, and conduct an individualized assessment of the patient's needs. Recipients must also be obligated to take any other action to accommodate the patient, which may include providing accessible transportation at no cost.<sup>102</sup>

- *MDE Question 10: The Department seeks information about other methods that recipients can use to make their programs and activities readily accessible to and usable by individuals with disabilities in lieu of purchasing, leasing, or otherwise acquiring accessible MDE.*

HHS proposes other options for alternative methods, such as referrals to other hospitals or provider locations. These proposals recognize that alternatives should not be significantly less convenient or result in higher costs. Without clear guidance on these requirements, patients are left with uncertainty about their rights. HHS must also consider other barriers individuals with disabilities may face, for example, limited accessible transportation options. However, there may be circumstances in which the referred location is actually more convenient for the individual. HHS must provide a clear and defined test for any alternative offered. In any case where an alternative option is necessary, the provider and staff must engage in an interactive process with the patient, which includes giving due consideration to the patient's preference, and conduct an individualized assessment of the patient's needs.<sup>103</sup> Recipients must also be obligated to take any other action to accommodate the patient, which may include providing accessible transportation at no cost.<sup>104</sup>

- *MDE Question 11: The Department seeks information regarding recipients' leasing practices, including how many and what types of recipients use leasing, rather than purchasing, to acquire MDE; when recipients lease equipment; whether leasing is limited to certain types of equipment (e.g., costlier and more technologically complex types of equipment); and the typical length of recipients' MDE lease agreements.*

Approximately 70 percent of medical equipment in the U.S. is leased, which provides a lower upfront cost for recipients and a more flexible option to replace equipment.<sup>105</sup> Lease contracts are generally three to five years in length, but a lessee often has the option to end the lease before the end of the contract. Especially with more technologically complex equipment, recipients may choose to lease the equipment so they can upgrade to the newest technology at the end of the lease. Lessees may also qualify for federal tax benefits, like IRS Section 179, to reduce costs. To reiterate, should a recipient renew their lease, the renewed contract must

adhere to the same scoping requirements as new equipment to ensure recipients do not use contractual agreements to avoid regulatory requirements.

- *MDE Question 12: The Department seeks information regarding whether there is a price differential for MDE lease agreements for accessible equipment.*

A financial burden alone is not an affirmative defense for failure to comply with accessibility requirements. As DOJ concluded, “the additional benefits that persons with disabilities will derive from greater safety, enhanced independence, and the avoidance of stigma and humiliation—benefits that the Department’s economic model could not put in monetary terms—are, in the Department’s experience and considered judgment, likely to be quite high.”<sup>106</sup> Even if a lease agreement for accessible equipment is more, one benefit of a lease is that the cost is spread out between the lease payments, without a higher upfront cost for the recipient.

- *MDE Question 14: If this rule were to apply to medical equipment that is not used for diagnostic purposes, Should the technical standards set forth in the Standards for Accessible Medical Diagnostic Equipment be applied to non-diagnostic medical equipment, and if so, in what situations should those technical standards apply to non-diagnostic medical equipment?*

For individuals with disabilities to have equal access, the technical standards must also apply to equipment not used for diagnostic purposes. Without applying the standards to equipment used for treatment, therapeutic, and rehabilitative medical care, people with disabilities will still be denied equal access to all medical programs and services. If the MDE Standards can be applied to equipment, such as, but not limited to, cancer treatment and dialysis chairs; surgical tables and chairs; rehabilitative tables and chairs; and any other medical treatment chairs and tables, people with disabilities will have equal access to the same medical care, programs, and services offered to those without disabilities. HHS must also ensure any at-home medical diagnostic or treatment equipment supplied by a recipient meets accessibility standards. Such examples would include, but not be limited to, CPAP machines, BiPAP machines, blood pressure monitors, and other digital equipment. All at-home equipment should be designed so an individual can use the equipment independently.

In addition, CCD urges HHS, in collaboration with the Access Board, to develop and issue standards for individuals with non-mobility disabilities, including sensory disabilities, intellectual and developmental disabilities, and individuals with multiple disabilities. For example, the introduced bipartisan Medical Device Nonvisual Accessibility Act (HR 1328)<sup>107</sup> requires covered devices to meet nonvisual accessibility standards. If passed, HHS should incorporate similar requirements into 504 regulations. Although qualified individuals with any type of disability must be offered equal opportunity to access medical programs and services, regulated entities would benefit from specific technical guidance on how to fulfill their obligations and make their services accessible.

- *MDE Question 14: If this rule were to apply to medical equipment that is not used for*

*diagnostic purposes, are there particular types of non-diagnostic medical equipment that should or should not be covered?*

All medical equipment, including non-diagnostic equipment, must provide equal access. With emerging technology, new medical equipment may be designed and manufactured. All current and new medical equipment must be accessible for people with disabilities. CCD again reiterates that HHS must develop standards, in collaboration with the Access Board, for non-mobility disabilities so all people with disabilities have equal opportunity to access medical equipment, including at-home equipment.

- *MDE Question 15: The Department seeks general comments on this proposal, including any specific information on the effectiveness of programs used by recipients in the past to ensure that their staff is qualified and any information on the costs associated with such programs.*

Individuals with disabilities report situations when providers have accessible equipment, but the staff does not know how to operate it. Without proper staff training, the accessible equipment is useless and both the patient and staff are at risk of injury. CCD strongly urges HHS to require comprehensive staff training for the safe use of accessible MDE, including training on effective communication with people with disabilities in plain language. All staff must be trained to safely use accessible MDE so the patient can use it independently. The cost of this training should be minimal, especially in comparison to the cost of an injury to patients or personnel. Hospital staff have a higher rate of injuries, even when compared to manufacturing and construction workers.<sup>108</sup> Proper training reduces the number of injuries to patients and staff, ultimately reducing costs for recipients.

We also recommend recipients consult with disability rights organizations and people with disabilities when developing training programs for best practices. Staff must be trained to ensure individuals with disabilities are treated with respect, dignity, and independence and will acknowledge the proficiency such patients have in understanding their own disability and needs. Recipients must also be required to hold consistent refresher trainings for all staff to maintain this necessary knowledge.

In addition, staff must be trained in what accessible equipment and accommodations may be needed, appropriately book and reserve the use of accessible equipment, and determine whether additional time or staffing may be needed for the appointment due to the use of accessibility features and/or other accommodations. For this process, recipients must maintain and properly update the accessible equipment inventory.<sup>109</sup>

- *MDE Question 16: The Department seeks public comment on whether there are any barriers to complying with this proposed requirement, and if so, how they may be addressed.*

Barriers to proficient staff training may include a lack of knowledge by the recipient in general on the use of accessible equipment, best practices in training staff on how to effectively communicate with patients with disabilities in plain language, and the types of accommodations needed for people with disabilities. To reduce these burdens, HHS should provide technical guidance, in consultation with disability rights organizations and people with disabilities; issue guidance on best practices for staff training, including how to communicate with patients in plain language; and provide guidance on best practices for engaging in an interactive process with individuals with disabilities in plain language. Although not covered under Section 504, HHS could collaborate with manufacturers to provide easy to understand instructions on how to use accessible equipment or encourage recipients to request instructions in their acquisition equipment contracts. In addition, the recipient's current booking system may not note which rooms, departments, or locations have accessible equipment. Although recipients' systems may vary, for ensuring the booking of accessible equipment, this must be required to ensure individuals with disabilities are properly and equally treated. Recipients must, therefore, maintain an up-to-date list of accessible equipment. Although the transition to a more detailed booking system may potentially result in some minimal upfront costs, it is the only way to ensure staff can properly provide access during the transition to 100 percent accessible equipment.

## **B. REVISED PROVISIONS ADDRESSING DISCRIMINATION AND ENSURING CONSISTENCY WITH STATUTORY CHANGES AND SIGNIFICANT COURT DECISIONS**

### **B.1 Definitions: Revisions to Subpart A (§84.10)**

#### ***B.1.1 "Auxiliary Aids and Services" (§84.10)***

**Recommendation:** Amend the definition of "Auxiliary aids and services" as noted in **bold** below:

(1) Qualified interpreters on-site or through video remote interpreting (VRI) services; notetakers; real-time computer-aided transcription services; written materials; exchange of written notes; telephone handset amplifiers; assistive listening devices; assistive listening systems; telephones compatible with hearing aids; closed caption decoders; open and closed captioning, including real-time captioning; voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), videophones, and captioned telephones, or equally effective telecommunications devices; videotext displays; accessible electronic and information technology; or other effective methods of making aurally delivered information available to individuals who are deaf or hard of hearing;

(2) Qualified readers, **digital readers**; taped texts; audio recordings; Braille materials and displays; screen reader software; magnification software; optical readers; secondary auditory programs (SAP); large print materials; accessible electronic and information

technology; or other effective methods of making visually delivered materials available to individuals who are blind or have low vision;

(3) Acquisition or modification of equipment or devices; and

(4) Other similar services, ~~and~~ actions, **and accessible formats may be considered as technological advancements are made.**

**Rationale:** To maintain consistency with Title II of the ADA, to update Section 504 consistent with the National Copyright Act as amended in 2018 by the Marrakesh Treaty Information Act[1] (which changed the term “specialized formats” to “accessible formats”), and to ensure individuals with disabilities are provided every opportunity to access the auxiliary aids they need, HHS must acknowledge that digital readers are quite common and should be specified. The addition of the new sentence, ‘Additional accessible formats may be considered as technological advancements are made’ is a helpful way to clarify that the list (and availability of updated technology to qualifying individuals) is flexible and that the list is not static under the law.

**Recommendation:** Support changes to Qualified Individual with a Disability: Paragraph (3) which proposes to make no distinction between public and private programs or activities.

**Rationale:** We support this proposal, consistent with the Department’s proposal to clarify that Section 504 applies to all recipients of Federal funding (See: CCD rationale under §84.38)

### ***B.1.2 “Direct Threat” (§ 84.10)***

In § 84.10(1), we agree with generally defining “direct threat” to be consistent with ADA Title II regulations (28 CFR § 35.104).

In § 84.10(2), we understand the rationale for defining “direct threat” with respect to employment to be consistent with ADA Title I regulations (29 CFR § 1630.2(r)) and recommend specifying in this definition that “A significant risk is high, and not just a slightly increased risk,” for full consistency with the DOJ’s definition of “direct threat” in the context of employment.<sup>110</sup>

We appreciate the Department’s incorporation of ADA Title II regulations and recognition that, for the law to achieve its goal of protecting people with disabilities from “discrimination based on prejudice, stereotypes, or unfounded fear,” it is essential to conduct an individualized assessment and ensure that any safety requirements “are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities.”<sup>111</sup>

We are concerned with the suggestion that a person determined to pose a direct threat is not “qualified,” for two reasons. First, it appears to conflate two separate threads of analysis. Whether an individual is qualified is a threshold question for a person with a disability to establish, whereas whether an individual poses a direct threat is an affirmative defense for a



recipient to establish. Second, and in the alternative, if the Department maintains this burden-shift, we recommend applying the direct threat analysis as set out in ADA Title II regulations at 28 CFR § 35.139<sup>112</sup> such that the commentary would read:

“Although persons with disabilities are generally entitled to the protection of this part, a person who poses a significant risk to the health or safety of others constituting a direct threat will not be “qualified” if reasonable modifications to the recipient's policies, practices, or procedures will not mitigate that risk.”

### **B.1.3 “Most Integrated Setting” (§ 84.10)**

- *Definitions (most integrated setting) Question 3: The Department requests comment on the need to include additional language in the definition of “most integrated setting.”*

In response to Definitions Question 3, we believe the definition of “most integrated setting” should be expanded and not be limited to interactions with non-disabled peers. Consistent with widely accepted Key Principles for Community Integration for People with Disabilities (2014),<sup>113</sup> it should read:

“The most integrated setting is a setting that enables people with disabilities to live as much as possible like people without disabilities.”

### **B.1.4 “Service Animals” (§ 84.10)**

The proposed definition provides a non-exhaustive list of examples of work or tasks a service animal might be trained to perform for individuals with various types of disabilities. The example regarding individuals with mental and neurological disabilities involves reference to impulsive or harmful behaviors, followed by discussion of crime deterrent effects. We recommend removing this example because it reinforces prejudice and discrimination against people with mental health conditions, as well as misperceptions that they are more violent or dangerous. Instead, we recommend using an example provided by the U.S. Department of Justice, such as sensing that an anxiety attack is about to happen and taking a specific action to help avoid the attack or lessen its impact.<sup>114</sup>

## **B.2 Revisions to Subpart C: Program Accessibility (§ 84.38)**

CCD supports language to require new construction and alterations adhere to standards that provide the greatest accessibility. Since HHS has not revisited Section 504 requirements for decades, the Department must also consider standards issued after a final rule's effective date. For example, in September 2022, the Access Board issued an ANPRM on self-service transaction kiosks.<sup>115</sup> If the Access Board and/or DOJ adopts a final rule on kiosk accessibility, HHS recipients should adhere to the most recent accessibility standards. HHS should reconsider and evaluate updated accessibility standards to ensure program access, including 2017 ICC A117.1. In addition, HHS should include language that recipients must comply with the most recent accessibility

standards for new construction or alterations or provide accessibility that is greater than the most recent standards.

We agree HHS should adopt the proposed Section 84.88 in application to program accessibility, which outlines fundamental alteration and undue burden defenses in accordance with the ADA.<sup>116</sup> The bar for such defenses must be high, and the recipient must still allow individuals with disabilities to participate in and benefit from the services, programs, or activities. If HHS finalizes a requirement that the decision must be accompanied by a written statement, it should also include a prompt timeframe for the decision. An individual must not be delayed access because they must wait for a written decision.

If a recipient must use an alternative to make its services accessible, the recipient must also take all steps necessary to provide such services in the most integrated setting.<sup>117</sup> In addition, in any case where an alternative option is necessary, the recipient must engage in an interactive process with the individual, which includes giving due consideration to the individual's preference, and conduct an individualized assessment of the person's needs.<sup>118</sup> In addition, if an alternative service or location is utilized, recipients must be obligated to take any other action to remove additional barriers due to the alternative, such as providing accessible transportation at no cost.<sup>119</sup>

### **B.3 Revisions to Subpart D: Childcare, Preschool, Elementary and Secondary, and Adult Education (§ 84.38)**

#### ***B.3.1 Application (§ 84.31)***

**Recommendation:** Maintain the proposal to add "childcare" to §84.31.

**Rationale:** CCD agrees, as noted by the Department, that Section 504 was intended to broadly reach any form of childcare, whether or not it would be considered "day care."

**Recommendation:** Maintain the proposal to change the heading of §84.38 to "Childcare, preschool, and adult education" and to add Child Care and Adult Education to the subpart heading to reflect what is contained in the two sections.

**Rationale:** CCD agrees that these changes are consistent with Section 504 and provide helpful clarification to the broad applicability of the law.

#### **Recommendations:**

- Maintain the clarification that Section 504 applies to all recipients of Federal funding, including public or private preschools, childcare centers, family childcare homes, and other entities that receive Federal funds including through a grant, loan, contract, or voucher.

- Maintain clarification that recipients must provide auxiliary aids and services; make reasonable modifications to their policies, practices, and procedures; and integrate children, parents, and guardians with disabilities into their programs.
- Maintain the clarification that recipients generally are subject to all the general and specific prohibitions against discrimination contained at proposed § 84.68.
- *Child Care, Preschool, Elementary and Secondary, and Adult Education Question 1: The Department wants to better understand potential impacts of the proposed rule on these recipients and requests comment on the application of the proposed rule to childcare providers and any potential barriers to compliance.*

CCD agrees with the Department that Section 504 applies to recipients of Federal funding, including public or private preschools, childcare centers, family childcare homes, and other entities that receive Federal funds including through a grant, loan, contract, or voucher. We support this clarification and agree this update will help ensure that the longstanding requirement that providers must not deny access or services based on a child’s disability remains intact and affirmed in the law. As we shared with Congress in 2021, CCD has a long-standing position that all childcare and preschool providers in receipt of Federal funding, whether directly from the state or indirectly through a third-party, must not be allowed to discriminate against infants, toddlers, and young children on the basis of disability.<sup>120</sup>

While the Department has generously indicated that “some childcare providers that receive financial assistance from HHS may not be familiar with these obligations,” it is CCD’s experience that children with disabilities actually experience a disproportionate share of discrimination in accessing childcare. As the Department knows, these children are more likely to live in poverty (or conversely, poor children are more likely to have a disability)<sup>121</sup>, children with disabilities and their families can struggle to both afford high quality childcare and to access it,<sup>122</sup> and these families are often faced with too few or no options for childcare especially for children ages 0-3 who have a disability, as well as their siblings.<sup>123</sup> We view the updates to Section 504 as vital to promoting access and protecting the civil rights of children.

### ***B.3.2 Education of Institutionalized Persons (§ 84.54)***

**Recommendation:** Revise the provision as **indicated**:

A recipient to which this subpart applies and that provides aids, benefits, or services to persons who are institutionalized because of disability shall ensure that each qualified individual with disabilities, as defined in § 84.10, in its program or activity is provided an appropriate education, consistent with the Department of Education section 504 regulations at 34 CFR 104.33(b) **regular or special education and related aids and services that**

**(i) are designed to meet individual educational needs of individuals with a disability as adequately as the needs of individuals without a disability are met and**

**(ii) are based upon adherence to procedures that satisfy the requirements of the Department of Education Section 504 regulations.**

Nothing in this section shall be interpreted as altering in any way the obligations of recipients under subpart D of this part.

**Recommendation:** Indicate in the preamble to this regulation that § 84.54: Education of Institutionalized Persons is to be interpreted consistent with both the requirements of the Department of Education Section 504 regulations and the Department of Justice’s regulations enforcing Title II of the Americans with Disabilities Act (ADA), including the regulations’ prohibition on “[a]fford[ing] a qualified handicapped person an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others.”

**Rationale:** CCD supports that individuals with disabilities who may be institutionalized must receive an appropriate education that provides equal opportunity and we appreciate the Department’s intent to ensure that all institutionalized school-aged children receive educational services no matter the setting. However, citing Section 504 regulations of the Department of Education, 34 CFR 104.33(b), to define appropriate education for institutionalized students raises a concern because the Department of Education has indicated their intent to amend regulations at 34 C.F.R. pt. 104, implementing Section 504 of the Rehabilitation Act of 1973. Given the likelihood of pending action by the Department of Education, CCD recommends the Department eliminate the specific reference and clarify that the requirements of both Section 504 and the ADA apply to educational services provided to institutionalized persons. Both recommended additions clarify the requirements of both laws with regard to institutionalized persons.

## **B.5 Subpart G: General Requirements**

### ***B.5.1 General Prohibitions Against Discrimination (§84.68)***

#### **B.5.1.1 Reasonable Modifications and Supported Decision-Making (§ 84.68(b)(7))**

We appreciate the Department’s express recognition of Supported Decision-Making (SDM) in its preamble discussion of NPRM section 84.68(b)(7), which addresses Section 504’s long-standing obligation that a recipient make reasonable modifications in policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability.<sup>124</sup> The preamble states that reasonable modifications in this context “may include, but are not limited to, permitting the use of supported decision-making or a third-party support, where needed by a person with a disability.”<sup>125</sup> Members of CCD’s Rights Task Force and its Guardianship Working Group have recommended this kind of recognition,<sup>126</sup> as have the delegates of the Fourth National Guardianship Summit.<sup>127</sup> The Department’s preamble also provides a definition of SDM that is based on the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA)<sup>128</sup> and provides useful examples of how SDM can be used in health care and human services.<sup>129</sup> It is important for the Department to underscore recipients’ obligations to provide reasonable modifications needed to ensure effective communication and informed choice, and that should include respecting the right of people with disabilities to use SDM. As indicated in our response to “Medical Treatment

Question 4,” given the involvement of the HHS Office of Civil Rights in addressing federal complaints surrounding discriminatory hospital visitor bans during the COVID-19 pandemic, we would recommend the Department also include an example highlighting recipients’ obligations to allow for designated support person(s) for people with disabilities who need them to enjoy equal access to health and human services and supports. Such reasonable modifications to policies and procedures have been linked to the use of SDM.<sup>130</sup>

### ***B.5.2 Maintenance of Accessible Features (§ 84.70)***

CCD agrees that maintenance of accessible features is necessary to ensure individuals with disabilities have an equal opportunity to access program services and benefits. Failure to maintain these features effectively denies access. The final rule, however, must clarify that maintenance of accessible features encompasses all accessibility features and disability accommodations, including, but not limited to, physical accessibility features and the provision of all disability accommodations, such as auxiliary aids and services. CCD supports the explicit inclusion of persisting obstructions or repeated mechanical failures. However, HHS should add that repeated mechanical failures for *any reason* violates Section 504.

### ***B.5.3 Service Animals (§ 84.73)***

We concur with the Department and believe that HHS should add a new “service animals” section to its regulation, which mirrors the ADA Title II regulations. As outlined in the NPRM, numerous court rulings have applied the same definitions and regulations surrounding service animals found under Title II of the ADA to interpretation of Section 504. This makes sense because, as the Department explains, these provisions are merely a specific application of the broader reasonable modification requirements. This rule does not alter entities’ obligations but provides much needed clarity and consistency for both covered entities and protected individuals—much like in the 2010 ADA regulations implementing Title II.<sup>131</sup> The use of service dogs is more and more common and is being used for a broader range of disabilities. The adoption of such regulations will help both service dog users and covered entities in ensuring that rights are protected, and abuses of the law do not take place. Additionally, we support the definition outlined in proposed § 84.10. Below we add our thoughts on the provided definitions to emphasize our support, and make some additional comments on the definitions and regulations provided.

#### **Proposed (§ 84.73(a))**

We support the Department’s recognition of the general rule that a recipient shall modify its policies, practices or procedures to permit the use of a service animal by an individual with a disability.

In the commentary regarding this section, we understand the recognition of the potential for fundamental alterations as proscribed by Title II of the ADA. Existing case law helps to define what a fundamental alteration includes. Although often unfounded, healthcare settings can

appear to be more complicated settings to analyze for whether the presence of a service dog constitutes a fundamental alteration because of potential health risks brought about by the presence of dogs. We believe the definition as stated under Title II provides an effective approach to address policies and practices that refuse access to animals while balancing situations where a policy modification may, in rare cases, constitute a fundamental alteration to the medical services offered at the entity.

#### Proposed (§ 84.73(b))

We agree with these exceptions, which clearly align with the language in the ADA regulations. This exception enables those with service animals to be more socially accepted and ensures that service animal handlers maintain their dog's behavior and cleanliness. We ask that either in the regulation or commentary, the Department clarify that the handler is typically the person with a disability. That is clearly what the proposed rule and the existing ADA regulations contemplate, as DOJ and courts have recognized.<sup>132</sup> This clarification would help prevent discrimination against minors and other people with disabilities who an entity deems incapable of acting as the handler of their service dog due to the age or due to false assumptions and stereotypes about their disability.

#### Proposed (§ 84.73(c))

This provision again aligns with Title II of the ADA. Though separating a person with a disability from their service dog has been shown to cause harm and is a denial of full and equal access,<sup>133</sup> this provision is appropriate because it does not completely deny access to the person with a disability in the limited cases where a service dog may be excluded under 84.73(b). Instead, the dog must vacate the premises and then the person can revisit the entity and receive the services without the animal. This ensures that patients seeking medical care, for example, will not be completely denied medical care if they need to temporarily remove their dog for any legitimate reason permitted by the rule.

#### Proposed (§ 84.73(d))

This provision also generally aligns well with the ADA. However, enforcement of the ADA regulations supports further clarification of this provision. Specifically, the statement that a service animal must be under the control of its handler is immediately followed by an explanation that a service animal must have a harness, leash, or other tether.<sup>134</sup> The relationship between these two sentences is clear: "a harness, leash, or other tether" are the primary means for a handler to keep a service dog under control. However, covered entities have tried to argue otherwise. Thus, clarification that tethering is generally sufficient to establish control is needed. Federal courts have also recognized that tethering is a form of "control."<sup>135</sup> In *Alboniga*, the court found that a six-year-old child who used a wheelchair controlled his service dog by being tethered to the dog in school.<sup>136</sup> The court held that the child controlled his service dog through tethering, regardless of the child's intellectual disability,

seizure disorder, physical impairments, or the fact that he needed “care and support for all aspects of daily living.”<sup>137</sup>

In addition, people with mental and communication disabilities are increasingly using service dogs. These service animals can be life changing and even lifesaving. But their handlers may not be able to issue verbal commands. Other people with disabilities cannot physically control the dog and do so through verbal or nonverbal means. We thus ask that the Department make explicit that “signals and other effective means” include gestures and nonverbal means of controlling a service dog. This aligns with the ADA regulations and case law.<sup>138</sup>

As long as the dog is not out of control, it should generally be deemed under the control of its handler. For example, the handler may issue a command to “stay” and then walk away for a period of time. If the dog follows the command and stays under control until the handler returns, it is under the control of its handler at all times. Many service dogs are trained to respond to the person with a disability who they serve. Indeed, the mere presence of that person may be sufficient to keep the dog under control. The service dog may be trained to stand, when the person stands, without a command. This is still a form of control.<sup>139</sup> As the Department notes, some service dogs are trained to assist during a seizure or interrupt dysregulated behaviors. Most, if not all, people cannot issue commands or direct their dog during a seizure, nor does it make logical sense for someone to direct a dog to prevent or interrupt their own behaviors. Though the person with a disability cannot actively issue commands during such an incident, if the dog is performing its duties and is not out of control, it is under the control of its handler, who is typically the person with a disability.

We appreciate the need for the dog to remain under control at all times. However, we do agree that in a health setting where an individual may need to separate from their dog for a specific treatment or circumstances may otherwise change quickly, if needed the handling of the dog can be shifted to a family member, support person, or friend as a reasonable modification. This protects the person’s right to access healthcare with their service dog, but can be adapted in the instance of a medical necessity. That said, if the dog remains under control during a temporary medical incident, like a seizure, the person with a disability remains the handler of the dog and the entity may not remove the dog or require another person to act as the handler. Doing so could be harmful and interfere with the dog’s training. There is also extensive research on the harmful impacts of separating a person with a disability from their service dog.<sup>140</sup> This should only occur when the conditions of 84.73(b) are all met.

#### Proposed (§ 84.73(e))

This too aligns with the ADA regulations. Enforcement of those regulations has shown some confusion about the meaning of this requirement. This has been analyzed by federal courts and is discussed in DOJ Guidance. Consistent with the existing guidance and case law, we ask that the Department clarify that “care or supervision” means routine animal care – such as feeding, watering, walking or washing the animal and generally refers to caring for the dog in the absence of the individual with a disability.<sup>141</sup> The DOJ guidance further explains: “If a service

animal must be separated from an individual with a disability . . . , it is the responsibility of the individual with the disability to arrange for the care and supervision of the animal during the period of separation.”<sup>142</sup> We agree and suggest including this in the commentary for clarity.

Courts have also clarified that providing some assistance to a person with a disability while they handle or care for their service dog may be required as a reasonable modification, as long as it does not rise to the level of a fundamental alteration and is consistent with the type of assistance provided to other people with or without disabilities. For example, if a hospital would provide assistance to a person with a disability by accompanying them to the bathroom, then it may be a reasonable accommodation to accompany the individual when they take their service dog outside to go to the bathroom. Doing so does not make the hospital the handler and does not run afoul of the care or supervision requirement of the regulation. This has come up in several court cases and thus clarification on this point would be helpful to covered entities and people with disabilities.<sup>143</sup>

#### Proposed (§ 84.73(f))

The two inquiries permitted under Title II of the ADA are widely known. They allow Title II entities to assess whether an animal is a service animal while not being too invasive when seeking information. We agree that these two questions should be applied to the 504 regulations. The explicit adoption of this test by covered entities will equip them with a tool to use when assessing potential abuses of the law.

We appreciate the Department acknowledging that a “recipient shall not require documentation, such as proof that the animal has been certified, trained, or licensed as a service animal” and otherwise incorporating key ADA provisions into the proposed rule. To address any remaining confusion, we recommend further clarifying that service animals are not required to wear a vest, ID tag, or specific harness to indicate that they are a service dog.<sup>144</sup>

#### Proposed (§ 84.73(g))

We support this component of the definition. However, it is imperative that the Title II requirements are explicitly incorporated into the Section 504 regulation for entities to ensure that people with disabilities can bring their dogs into such entities without facing discrimination. Therefore, we recommend the Department incorporate DOJ guidance that service animals must be allowed in medical settings, including patient rooms and anywhere else in a hospital the public and patients are allowed to go.<sup>145</sup>

#### Proposed (§ 84.73(h))

This too aligns with the Title II ADA regulations. People with disabilities who use a service dog should never be asked or required to pay a surcharge when accessing services with their service dogs. This is as necessary in medical settings as in other settings; we would never want someone to be dissuaded from seeking medical care because of a potential additional fee.



### Proposed (§ 84.73(i))

We accept the addition of miniature horses under Section 504. This addition under Title II has worked well. We agree that there are legitimate circumstances where an alternative is needed to a dog. We recommend that the additional circumstances in assessing the feasibility as proscribed in Title II of the ADA are also highlighted in these 504 regulations. For instance, if a particular miniature horse appears to be too large for a particular setting, the covered entity should be able to utilize the assessment tools described here to decide if the individual's requested accommodation is reasonable.

#### ***B.5.4 Mobility Devices (§ 84.74)***

CCD strongly agrees that individuals with disabilities must be permitted to use wheelchairs (including manual wheelchairs, power wheelchairs, and electric scooters) and manually-powered mobility aids (including walkers, crutches, canes, braces, and other similar devices) in all public areas.<sup>146</sup> HHS should adopt the DOJ's definition of wheelchair and other power-driven mobility device.<sup>147</sup> Currently, some recipients use blanket bans of power wheelchairs, including nursing homes, excluding the individual's access to programs and services.<sup>148</sup> A ban of mobility devices effectively excludes the individual.

#### ***B.5.5 Direct Threat (§ 84.75)***

We appreciate the Department's goal of adding clarity to "direct threat" by defining it to be consistent with ADA Title II regulations and recommend adding language from those regulations to further achieve this goal. Specifically, we propose **§ 84.75(a)** to read:

"This part does not require a recipient to permit an individual to participate in or benefit from the programs or activities of that recipient when that individual poses a direct threat **to the health or safety of others**.<sup>149</sup> A recipient may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities. However, the recipient must ensure that its safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities."<sup>150</sup>

For the same reason, we recommend adding language and propose **§ 84.75(b)** to read:

"Except as provided in paragraph (c) of this section, in determining whether an individual poses a direct threat **to the health or safety of others**, a recipient must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk."<sup>151</sup>

## **Direct Threat Commentary**

As noted above in comments to **§ 84.10 (Direct Threat)**, we appreciate the Department’s recognition of the importance of protecting people with disabilities from discrimination based on prejudice, stereotypes, or unfounded fear; and are concerned with the suggestion that a person determined to pose a direct threat is not “qualified.”

From our extensive collective experience in providing direct client services to people with disabilities and enforcing Section 504 and the ADA through litigation, the direct threat defense is often misunderstood, overused, and misconstrued. For example, it has been inappropriately used to justify blanket bans on wheelchairs,<sup>152</sup> power wheelchairs,<sup>153</sup> and other mobility assistive devices.<sup>154</sup> This is a misapplication of the direct threat defense based on generalizations and stereotypes and is not supported by the language of the statute or regulations. We ask HHS to clarify in the commentary that the direct threat analysis should be focused on the individual and requires a fact-specific, individualized assessment. It should not and cannot be used to justify or support blanket bans on wheelchairs, power wheelchairs, or other mobility assistive devices. Including this language in the commentary is consistent with case law, will provide clarification to recipients of their duties, and notify individuals of their rights.

### ***B.5.6 Integration (§ 84.76)***

We greatly appreciate the Department’s attention to the critical issue of integration and strongly endorse this section of the Proposed Rule as necessary to implement Section 504 and the Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). The commentary in the Proposed Rule presents a compelling rationale and a persuasive legal analysis that is consistent with the case law of Section 504. We applaud the Department for including these sections of the regulations.

The comments below propose clarifications, modifications, or additions to regulatory and commentary language, as well as respond to specific requests for comment.

#### **B.5.6.1 Segregated Setting (§ 84.76(c))**

The definition of “segregated setting” should include a reference to individual choice, since such settings often, or even almost always, restrict the ability of people with disabilities to make choices. Also, the definition should recognize that relevant restrictions or limitations on individual choice are not limited to those in formally adopted policies but also include those reflected in the setting’s practices, as the U.S. Department of Justice has recognized.<sup>155</sup>

We propose that the definition of “segregated setting” be:

“Segregated settings include, but are not limited to, settings populated exclusively or primarily with individuals with disabilities; that provide for daytime activities primarily with other individuals with disabilities; or that are characterized by regimentation in daily activities, a lack of choice or privacy, or policies or practices that limit individuals’ ability to engage freely in community activities or to manage their own activities of daily living.”

- *Integration Question 1: In the preamble of the proposed definition of “most integrated setting,” we solicit comments on whether the definitions should be expanded.*

In response to Integration Question 1, and as noted above in section 84.10, Definitions Question 3, we propose that the definition of “most integrated setting” read as follows:

“The most integrated setting is a setting that enables people with disabilities to live as much as possible like people without disabilities.”

This would bring the definition further in line with the intent of the ADA,<sup>156</sup> guidance from DOJ and HUD,<sup>157</sup> and broadly-endorsed Key Principles for Community Integration for People with Disabilities (2014).<sup>158</sup>

#### B.5.6.2 Specific Prohibitions (§ 84.76(d))

We believe that the narrative concerning examples of discrimination based upon disability (pp. 63484-86) is extremely helpful, and applaud the Department for incorporating principles from both case law and DOJ Guidance. We suggest that three additional examples based on legal principles and case law be included that reflect current challenges to individuals having access to the most integrated setting appropriate to their needs. These examples are designed to affirm the relevance of systemic barriers and practices, the inappropriateness of a jurisdiction failing to offer services in the most integrated setting unless an individual has “applied” for community services, and the importance of ensuring that people can make an informed choice of where to live and receive services.

To address these issues, we recommend that the Preamble (pp. 63484-86) include the following:

“A recipient has an affirmative obligation to administer its services and/or system of services in a manner that provides all individuals with disabilities access to the most integrated setting appropriate to their needs. Compliance with this obligation should be assessed across the recipient’s service system. Assessing whether a recipient’s policies and practices allow individuals to live and receive services in the most integrated setting can, and normally should, be determined on a group or class-wide basis. Such a determination may rely on expert opinion and other evidence demonstrating that in the recipient jurisdiction or elsewhere, similarly-situated persons have been served in, or have benefitted from, more integrated settings. Normally, the actual transition to a

more integrated setting will be accomplished through a person-centered planning process that considers the individual's preferences and identifies the amount and frequency of the services the individual needs to live or receive services in that setting. There is no requirement on the part of the individual with a disability to demonstrate the availability of a non-institutional setting. In addition, the recipient has an obligation to make reasonable modifications to an existing, non-institutional setting so that the non-institutional setting meets the individual's needs.

Given the recipient's affirmative obligation to administer its services and/or system of services in a manner that provides individuals with disabilities access to the most integrated setting, people with disabilities who live or receive services in segregated settings need not request or formally apply for community services to be covered by these regulations or obtain access to the most integrated setting.

The recipient's affirmative obligation to administer its services in the most integrated setting requires that individuals in segregated settings, and those at serious risk of entering segregated settings, be provided a meaningful, effective, and informed choice to live or receive services in the most integrated setting. An individual cannot be characterized as "opposing" an integrated setting unless the individual has made a knowing and informed choice, including, as appropriate, with the assistance of Supported Decision Making, to remain in a segregated setting. Opposition can only be determined if the individual is offered appropriate services in an integrated setting that would meet their needs. Individuals with disabilities prefer to live in integrated settings. Hence, a recipient should presume that individuals would choose to live in an integrated setting, unless the individual has clearly and knowingly stated that they do not want to receive services in an integrated setting and knowingly waived the right to live in the most integrated setting. The recipient's duty to make reasonable modifications to its services and programs does not depend upon the individual requesting a modification of a recipient's program."

**§ 84.76(d)(4):** We agree with HHS, DOJ, and the numerous circuit courts that a plaintiff need not wait until the harm of institutionalization or segregation occurs in order to bring a claim and seek prospective injunctive relief. It would be helpful to covered entities, advocates, and courts to clarify that "serious risk" includes an element of probability (likely to happen) and an element of temporality (in the foreseeable future). This is consistent with DOJ guidance, the weight of the case law, and what we have learned from litigating Olmstead cases. We also recommend that these key concepts be incorporated into the Specific Prohibitions in section **84.76(d)** of the regulations, as follows:

**(5)** Requiring individuals to request or formally apply for services in an integrated setting as a pre-condition to the individual's being provided access to the most integrated setting or the recipient's obligation to provide such access.

**(6)** Failure to provide individuals a meaningful and effective choice whether to live in more integrated settings, including through the provision of relevant information in a

manner understandable to the individual, opportunities to visit and explore more integrated settings. The process of informing and making choices should accommodate the individual's disability and address reluctance to live in an integrated setting based on a history of institutionalization or other vestiges of segregation.”

#### B.5.6.3 Civil Rights Obligations as Distinct from Medicaid Law and Regulations

We strongly support the assessment in the preamble to the proposed rule that civil rights standards apply independently to all situations where people with disabilities receive or are eligible for healthcare, including circumstances in which a covered entity is providing healthcare in accordance with Medicaid. CCD believes that Section 504's civil rights standards apply equally to Medicare and any other federal or state program or activity that involves federal financial assistance to healthcare entities. While federal agency officials, state Medicaid representatives, and entities such as hospitals and Medicare Advantage plans may have a wide range of expertise in various interrelated topics such as the administration and delivery of healthcare services, eligibility and enrollment of specific populations, coverage practices, treatment standards, and so forth, they do not necessarily have expertise in the civil rights that accrue to enrolled and eligible beneficiaries. The full panoply of entities that receive federal financial assistance in healthcare, including Medicare program providers, should be explicitly mentioned in the 504 rule so that they can clearly understand that they are independently responsible for adherence to the final Section 504 nondiscrimination rule.

We recommend that the rule include examples that capture the application of standards for receiving temporary periods of rehabilitation care, nursing home level-of-care, or durable medical equipment through Medicare Advantage Plans that discriminate against Medicare beneficiaries on the basis of having a disability, needing particular kinds of medications, or failing to meet an arbitrary service condition such as use in the beneficiary's home. The consistent failure to provide Medicaid and Medicare beneficiaries with needed services, including mental health services, treatments, and equipment quickly leads to decreased health and function that can put both Medicaid and Medicare enrollees at serious risk of unnecessary institutionalization. The two programs together provide critical elements of community-based healthcare to people with disabilities and older adults, ranging from short-term and long-term home and community-based services to regular preventive care, from wheelchairs to addiction-treatment services to maternal care. These services are the “flip side” of institutional care and when they are covered by providers who understand what it means to ensure that services are provided in an integrated setting, the programs help ensure that people with disabilities can remain living safely, independently, and productively in their communities.

#### B.5.6.4 Civil Rights Obligations Continue During Public Health Emergencies and Disasters

Public health emergencies and disasters, in which people with disabilities experience a high rate of institutionalization in violation of the Olmstead integration mandate, are also critical junctures that highlight the disparity between Medicaid law and civil rights obligations. Any rule whose goal is mitigating Olmstead noncompliance must specifically address this. The federal

government delineates how and why disabled people are institutionalized in disasters in detail in the 111-page National Council on Disability (NCD) report *Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters*. Through this report, “NCD examined available data from several major storms and disasters and found that people with disabilities are frequently institutionalized during and after disasters due to conflicting federal guidance; a lack of equal access to emergency and disaster-related programs and services; and a lack of compliance with federal law.”<sup>159</sup>

Institutionalization of disabled people in restrictive environments disproportionately occurs throughout the disaster cycle. For example, emergency departments, first responders and disaster shelters frequently refer or transfer disabled people to nursing facilities during disasters. Reasons why federally funded emergency response programs refer or transfer disabled people to nursing facilities include: structural inaccessibility of transportation and shelters, access to power; absent or inadequate mandated personal assistance at shelters; bias that disabled people belong or are safer in nursing facilities as opposed to the community; and separation from family members, community support providers, and personal assistance services. The latter especially occurs when people with disabilities are sent to segregated so-called “special” or “medical” needs shelters. Segregated shelters, although they theoretically offer additional services, have been consistently found to be inadequate to protect disabled people from harm. This includes exposure to infectious diseases, such as COVID-19; inadequate health maintenance; lack of effective communication access; and separation of disabled people from family and community support, including the benefits of integration. This can result in transfer to nursing institutions. Further, it is not unusual for these segregated facilities to turn away disabled people who have been successfully living in the community because their needs are perceived as too great (oxygen use, uninterrupted power, personal assistance, and other non-acute medical care).

Disabled people are also referred to nursing facilities by hospitals during disasters and public health emergencies. This is despite a clear directive from the DOJ stating, “Civil rights protections and responsibilities still apply, even during emergencies. They cannot be waived.”

According to CMS, “consistent with the integration mandate of Title II of the ADA and the *Olmstead vs LC* decision, States are obligated to offer/ provide discharge planning and/or case management/ transition services, as appropriate, to individuals who are removed from their Medicaid home and community based services under these authorities during the course of the public health emergency as well as to individuals with disabilities who may require these services in order to avoid unjustified institutionalization or segregation. Transition services/ case management and/or discharge planning would be provided to facilitate these individuals in their return to the community when their condition and public health circumstances permit.”<sup>160</sup>

However, flying in the face of these hard-won civil rights protections, according to the NCD report, “the issuance of waivers by the Centers for Medicare and Medicaid (CMS) allows states to place disaster-impacted people with disabilities into institutional settings for the

convenience of emergency managers and health care providers even though these individuals had not developed healthcare needs requiring hospital or nursing home level care.”<sup>161</sup>

In public health emergencies declared by the HHS Secretary, blanket waivers provided under Section 1135 of the Social Security Act are used to arbitrarily transfer individuals to a Skilled Nursing Facility directly from their home, a shelter or an emergency department. The waiver is also used to transfer people from acute care hospital beds to long term care facilities due to the hospital’s perceived need for the hospital bed, not due to the individual’s level of care needs. This is done without developing discharge plans that will provide disabled people services in the community that are most appropriate to their needs. During the COVID-19 Public Health Emergency, there was constant transfer of people with disabilities into nursing facilities to make room in hospital beds. This denied individuals the right to be served in the most integrated setting appropriate to their needs. Individuals were often placed in environments with extreme levels of uncontrolled COVID-19 infection, and dangerous lack of trained and vaccinated staffing in facilities already cited by CMS for egregious failure to manage infectious diseases, staffing levels and access to personal protective equipment.

In order to address findings of the federal government in its NCD report and provide consistency within HHS, the rule must address ways to mitigate discrimination against people with disabilities via institutionalization, explicitly inclusive of discrimination in public health emergencies and disasters. We recommend that the rule include language clarifying that the allowability of a practice through a Public Health Medicaid emergency waiver is not evidence that the practice meets the obligations set forth by Section 504’s integration mandate, nor does it obviate the state’s responsibility to meet those obligations.

Institutionalization is far from the only form of discrimination that disabled people experience in disasters, with significant and often catastrophic health consequences. Throughout disasters discrimination is pervasive, largely due to a lack of enforcement. Notifications of disasters and emergencies are consistently inaccessible. Accessible transportation is often not provided when transportation is offered to people without disabilities. Websites are consistently inaccessible to people who use assistive technology and are attempting to gain information about disasters and emergencies. It has been common that people could not register for COVID-19 vaccines, as an example of the failure of effective communication access in public health emergencies.

#### B.5.6.4 Fundamental alteration (§ 84.76(e))

We appreciate the Department’s recognition that providing services beyond what a State currently provides under its Medicaid program is not, in and of itself, a fundamental alteration. In particular, we agree that a state increasing the number of individuals it may serve in a particular Medicaid waiver program (expanding “the cap”) is not, in and of itself, a fundamental alteration. The fact that Medicaid permits a State to limit the number of people it will serve in a

waiver program does not exempt the State from serving additional people in the waiver program to comply with the ADA and Section 504.

We recommend that HHS make explicit in the preamble to the final regulation that increasing the “cap” of a waiver program does not constitute, in and of itself, a fundamental alteration, by clarifying the first sentence of the first new paragraph on p. 63487 as follows:

“Providing more of the same services that a State currently provides under its Medicaid program, including through a waiver, generally is not a fundamental alteration. For example, the fact that a State is permitted to “cap” the number of individuals it serves in a particular Medicaid waiver program does not excuse the State from serving additional people under the waiver, including by increasing the cap of the waiver program, as needed to comply with the ADA and Section 504. Increasing the “cap” of a waiver program does not in and of itself constitute a fundamental alteration of a State’s program.”

- *Integration Question 2: We seek comment on what may constitute a fundamental alteration for recipients who are not public entities, for example, an individual skilled nursing facility responsible for identifying and preparing individual who can and want to be discharged to available community-based services.*

In response to Integration Question 2, we believe it may constitute a fundamental alteration for recipients who are not public entities to provide entirely new services that the recipient has not provided in the past and is not otherwise required to provide.

On the other hand, we agree with HHS’s recognition both in this rulemaking and in 2016 Long-Term Care Facility Guidance that “[u]njustified segregation can include continued placement in an inpatient facility when the resident could live in a more integrated setting.” Thus, jurisdictions should require facilities to actively facilitate discharge, including by identifying and providing services to prepare individuals who can and want to be discharged to a community-based setting. It is not a fundamental alteration for facilities to engage in discharge planning or provide services to prepare individuals for discharge.

In fact, it is not even a modification. Both hospitals and nursing facilities are required by federal law to engage in appropriate discharge planning. Nursing facilities in particular are required to engage in “comprehensive person-centered care planning” under federal regulations, including the requirement to “develop and implement an effective discharge planning process that focuses on the resident’s discharge goals, the preparation of residents to be active partners and effectively transition them to post-discharge care, and the reduction of factors leading to preventable readmissions.”<sup>162</sup> We recommend HHS reiterate that a recipient’s compliance with



care planning obligations under other law does not exempt its discharge planning from scrutiny under Section 504.

We recommend that HHS consider additional examples of the types of supports and activities that a facility may be required to provide to help an individual transition to the community beyond what is already required under CMS regulations and guidance.

## C. ADDITIONAL COMMENTS FOR CONSIDERATION

### C.1 Additional Regulatory Language and Guidance on the Phrase “Solely by Reason of Her or His Disability.”

In recent years, the phrase “solely by reason of his or her disability” found in Section 504 has become a textual battleground in cases that threaten to gut disability civil rights. Despite the reasoning by the Supreme Court in *Alexander v. Choate*, 469 U.S. 287 (1985), the nature of disability discrimination, and the text of the 1977 regulations – adopted with the oversight and approval of Congress – and dozens of other agency rules, lawyers for Section 504 and Section 1557 defendants claim that the phrase means that *only* intentional discrimination is prohibited, and that other forms of discrimination are not actionable under the law.<sup>163</sup> The “solely” arguments persist, even though the design of systems that discriminate against and exclude people with disabilities is inherently intentional. *Cf. Schmitt v. Kaiser Found. Health Plan of Wash.*, 965 F.3d 945, 954 (9th Cir. 2020). The disability community has expended extraordinary resources fighting this false and ahistorical construction of Section 504.

If successful, these arguments would devastate the scope of prohibited disability discrimination. “Discrimination against the handicapped was perceived by Congress to be most often the product, not of invidious animus, but rather of thoughtlessness and indifference – of benign neglect.” *Alexander v. Choate*, 469 U.S. 287, 295-96 (1985). A sidewalk without a ramp denies access to a person in a wheelchair, regardless of intent. Congress in Section 504 of the Rehabilitation Act of 1973 sought to remedy just such discrimination.

The Agency’s proposed regulations include the phrase within proposed Section 84.68(a) but include no additional regulatory language defining the language. *See* 88:177 Fed. Reg. at 63505 (“No qualified individual with a disability shall, solely on the basis of disability, be excluded from participation in or be denied the benefits of the programs or activities of a recipient, or be subjected to discrimination by any recipient.”). The proposal does include helpful language in the introductory material, which states: “As used in this part, solely on the basis of disability is consistent with, and does not exclude, the forms of discrimination delineated throughout the rule. 88:177 Fed. Reg. at 63473; *see also id.* at 63474 (containing helpful discussion of *Alexander v. Choate*).

We ask that the Agency provide additional regulatory language and guidance on the phrase “solely by reason of his or her disability” that reflects case law, statutory purpose, and Congressional action. For example, the regulations could include text such as:

“Solely on the basis of disability” means that there is a demonstrable relationship between the discrimination alleged and the disability.

As used in this part, “solely on the basis of disability” includes the forms of discrimination delineated herein, including discrimination that results from thoughtlessness, indifference, and benign neglect, practices that have the effect of discrimination, and unintentional disparate-impact discrimination.

“Solely on the basis of disability” shall not be construed to lead to or require anomalous results, such as excluding claims where nondiscrimination requires the expenditure of funds, as such expenditure was clearly contemplated by the statute, or where the cited basis for discrimination cannot be extricated from the disability itself.

It would be enormously helpful for the Agency to provide regulatory language that explicitly defines and clarifies the statutory phrase in favor of broad coverage, as Congress intended.

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

## **C.2 Section 1557**

Section 1557 of the Affordable Care Act is the most important and specific nondiscrimination provision operating at the junction of disability rights and healthcare since the passage of the ADA. As noted in the preamble to the 2022 Notice of Public Rulemaking on Section 1557, “Title VI, Section 504, and the Age Act apply to *all* federally funded programs or activities, Section 1557 applies only to *health* programs or activities.”<sup>164</sup> While Section 1557 cites to and incorporates the discrimination grounds and enforcement mechanisms available under Section 504, HHS has recognized that current regulations “provide[] no guidance on how covered

entities are to implement their compliance responsibilities under Section 1557 and, in particular, whether those responsibilities are the same as, or deviate from, their compliance responsibilities under... Section 504... Rather, it generally states the nondiscrimination requirements of Section 1557 by restating the statutory language of 42 U.S.C. 18116(a), followed by stating that the grounds prohibited are the grounds found in... Section 504....The resulting uncertainty is particularly stark for procedural requirements."<sup>165</sup>

Enacted 37 years after Section 504 and 20 years after the ADA, Section 1557 can and should be seen as an expression of the will of Congress concerning the right of people with disabilities to be free of discrimination in the programs or activities of entities that provide health-related services, health insurance coverage, or other health-related coverage.<sup>166</sup> The wording of Section 1557 itself, which sweeps in “credits, subsidies, and contracts of insurance” as forms of federal financial assistance, broadcasts its intent to require nondiscrimination of health insurance issuers and not only the health service providers that have traditionally been the focus of Section 504 and the ADA. Moreover, the Secretary of HHS is given authority to enact regulations for the interpretation, monitoring, and enforcement of both Section 1557 and Section 504. Since the current proposed rule is intended to update and clarify the operation of Section 504 in light of key legislation, cases, and world events such as the COVID-19 pandemic, we strongly urge OCR to further parse out in this proposed rule how Section 504 and Section 1557 work together to protect people with disabilities from common discriminatory barriers that arise across multiple types of healthcare entities that function in the complex US healthcare system.

We recommend that HHS OCR incorporate provisions that will explicitly recognize the purpose and intent of the following nondiscrimination sections from the 1557 NPRM and apply them to the “broader range of programs and activities by recipients of Federal financial assistance”<sup>167</sup> that fall under Section 504.

### ***C.2.1. Nondiscrimination in the use of automated decision-making tools and systems***

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

Similarly, clinical guidance tools that point to the existence of multiple providers as a predictive risk-factor for opioid abuse fail to consider how people with multiple and significant disabilities will have multiple healthcare providers.<sup>168</sup> In another example, the historic and ongoing lack of functional disability data in health records means that decision-making tools and systems have

not been adequately trained to recognize how factors such as the use of personal care assistance are inadequately recognized in the allocation of home and community-based services and supports, including care coordination. Language in regulations enacted under Section 504 does not have to simply echo proposed language for a Section 1557<sup>169</sup> rule given the broad reach of Section 504 and recipients who engage in multiple kinds of decision-making, from medical treatment to family interventions to benefit eligibility and coverage.

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

### ***C.2.2 Benefit design and related concepts***

The preamble to the proposed rule states that “this rule does not relate to benefit design or other health insurance coverage issues.”<sup>170</sup> However, benefit design does not only conceptually apply to health insurance coverage. The design and delivery of health and health-related services is greatly impacted by multiple factors such as the quality and depth of provider networks, the use of utilization management tools, the use of automated decision-making tools and systems, the choice and application of equity and quality measures, how service denials can be appealed, how patient data is recorded and aggregated, and so forth. Conceptually, it can be difficult to distinguish where “benefit design” ends and where these myriad aspects of service delivery and accessibility begin, but Section 504 must be able to reach the many barriers for people with disabilities that can be embedded in all these different facets of health and human service delivery. There is no reason to disavow benefit design from the reach of the proposed rule, and every reason to follow the proposed Section 1557 rule's lead in embedding key aspects of the proposed rule such as the integration mandate as a required aspect of all these related concepts. We recommend modifying the assertion in the preamble that the proposed rule does not relate to benefit design, or deleting it altogether.

### ***C.2.3 The collection of functional disability data for demographic purposes***

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

quality analyses, including information on whether and how people with disabilities received accommodations needed for equally effective medical treatment.

### **C.3 Section 504 and Complaint-Driven Compliance**

While we recognize that compliance with Section 504 is complaint-driven, we are also aware that expecting marginalized people to file complaints about the discrimination they are experiencing during the most difficult moments of their lives is an absurd requirement. This assumes that people have the wherewithal, information, and even access to file a complaint. This is even truer for people with disabilities who have other marginalized identities such as being Black, Brown or Indigenous, being LGBTQIA+, or unhoused. The Department of Justice recognized that relying on complaints alone to enforce civil rights was not adequate when it launched Project Civic Access. With a goal to facilitate enforcement of the ADA, and in many situations Section 504, this has become a tool for compelling compliance. This is primarily accomplished through settlement agreements with the DOJ and is necessary for enforcement of Section 504. To successfully facilitate compliance with HHS obligations under Section 504, a similar tool must be developed, funded, adequately staffed, and fully implemented.

### **CONCLUSION**

Nearly 50 years after passage of the Rehabilitation Act, these updates are needed now more than ever. COVID and the aging population has led to a significant increase in the numbers of people with disabilities, including Black, Indigenous and other people of color and members of the LGBTQIA+ community who continue to face barriers to equal and just access to care. COVID will not be the last pandemic or other emergency this nation faces, and we cannot repeat the mistakes of the past when encountering future threats. We must continue to uphold the intent of the Rehabilitation Act and Section 504 and ensure discrimination in health care, child welfare programs, and the broad range of other covered activities and programs is not tolerated and every person's life is valued.

Thank you again to the HHS leadership, Office of Civil Rights and staff for your significant efforts to propose these rules. Swift adoption of a final rule with our considerations taken into account could improve access and a higher quality of life for all people with disabilities in the United States and territories. We greatly appreciate the opportunity to provide comments on this consequential and historic rulemaking.

Sincerely,

A Better Balance

Academy of Nutrition and Dietetics

Allies for Independence

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union  
American Council of the Blind  
American Foundation for the Blind  
American Music Therapy Association  
American Occupational Therapy Association (AOTA)  
American Therapeutic Recreation Association  
Amputee Coalition  
Assistive Technology Industry Association (ATIA)  
Association of Assistive Technology Act Programs (ATAP)  
Association of People Supporting Employment First (APSE)  
Association of University Centers on Disabilities  
Autism Society of America  
Autistic Self Advocacy Network  
Autistic Women & Nonbinary Network  
Bazelon Center for Mental Health Law  
Caring Across Generations  
CAST  
Center for Learner Equity  
Center for Medicare Advocacy  
Center for Public Representation  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Christopher & Dana Reeve Foundation  
CommunicationFIRST  
Community Catalyst  
Council of Parent Attorneys and Advocates  
Council of State Administrators of Vocational Rehabilitation (CSAVR)  
Cure SMA  
Disability Equity Collaborative  
Disability Rights Education and Defense Fund (DREDF)  
Diverse Elders Coalition  
Eggleston  
Epilepsy Foundation  
Family Voices  
GO2 for Lung Cancer  
Hearing Loss Legal Fund  
Justice in Aging  
Lakeshore Foundation

Medicare Rights Center  
Mental Health America  
Muscular Dystrophy Association  
National Alliance on Mental Illness  
National Alliance to End Sexual Violence  
National Association for Rights Protection and Advocacy  
National Association of Councils on Developmental Disabilities  
National Center for Law and Economic Justice  
National Center for Learning Disabilities  
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)  
National Council on Independent Living (NCIL)  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Health Law Program  
National Organization of Social Security Claimants' Representatives (NOSSCR)  
National PLAN Alliance (NPA)  
National Respite Coalition  
Pandemic Patients  
Paralyzed Veterans of America  
Perkins School for the Blind  
Quality Trust for Individuals with Disabilities  
RespectAbility  
SAGE  
SourceAmerica  
TASH  
The Advocacy Institute  
The American Speech-Language-Hearing Association  
The Arc of the US  
The Partnership for Inclusive Disaster Strategies  
United Spinal Association  
US International Council on Disabilities  
World Institute on Disability  
Young Center for Immigrant Children's Rights

---

<sup>1</sup> See Daniel Werb *et al.*, *The Effectiveness of Compulsory Drug Treatment: A Systematic Review*, 28 INT'L J. OF DRUG POLICY 1-9 (2016) (concluding that evidence, on the whole, does not suggest improved outcomes related to compulsory drug treatment approaches, with some studies suggesting potential harms and recommending the prioritization of non-compulsory treatment modalities); see also Steven P. Segal, *Protecting Health and Safety with Needed-Treatment: The Effectiveness of Outpatient Commitment*, 93 PSYCHIATRY Q. 55 (Mar. 2022) (meta-analysis of outpatient commitment studies around the world attributing positive outcomes to enriched community services and equal access to medical procedures for health conditions, rather than the involuntary outpatient commitment system itself, and noting that involuntary outpatient commitment did not improve health outcomes for those who otherwise had access to care).

<sup>2</sup> U.S. FOOD & DRUG ADMIN., *Final Rule: Banned Devices; Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior*, 85 Fed. Reg. 13,312 (Mar. 6, 2020), <https://www.govinfo.gov/content/pkg/FR-2020-03-06/pdf/2020-04328.pdf>.

<sup>3</sup> See, e.g., NPRM at n. 83-87 (citing the HHS OCR's resolution of complaints and the provision of related technical assistance in Tennessee, Utah, and North Carolina).

<sup>4</sup> See NAT'L COUNCIL ON DISABILITY, *Medical Futility and Disability Bias*, at 12 (November 20, 2019), [https://ncd.gov/sites/default/files/NCD\\_Medical\\_Futility\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf) (stating "[m]edical and health professional schools should include disability competence as a component of or in addition to cultural competence training. Medical and health professional schools should be physically and programmatically accessible for students with disabilities in order to facilitate diversity among healthcare providers" and cited in NPRM at n. 65).

<sup>5</sup> *Id.* at 12 (recommending development of an independent review panel, especially in cases of medical futility decisions, that is not associated with the provider or facility and whose composition reflects racial, ethnic, and disability diversity).

<sup>6</sup> See NPRM, Section 84.56(c) (1)(i) ("Nothing in this section requires the provision of medical treatment where the recipient has a legitimate, nondiscriminatory reason for denying or limiting that service, or where the disability renders the individual not qualified for the treatment.")

<sup>7</sup> See, e.g., Lisa I. Iezzoni *et al.*, *Physicians' Perceptions of People with Disability and Their Health Care*, 40 Health Aff. 297 (Feb. 2021), <https://pubmed.ncbi.nlm.nih.gov/33523739/> (citing GL Albrecht *et al.*, *The Disability Paradox: High Quality of Life Against All Odds*, 48 Soc. Sci. Med. 977 (1999) and cited at NPRM at n. 67).

<sup>8</sup> As noted in the preamble, certain assessment tools employed during the pandemic, like the Sequential Organ Failure Assessment (SOFA), can be discriminatory as applied, without reasonable modifications, including scoring for individuals whose underlying disability includes non-speaking or having paralysis.

<sup>9</sup> See U.S. DEP'T HEALTH & HUM. SERVS., *Press Release: OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19* (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolvescomplaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>.

<sup>10</sup> See NPRM at 63,395.

<sup>11</sup> See, e.g., Emily Cleveland Manchanda, Cheri Couillard, and Karthik Sivashanker, *Inequity in Crisis Standards of Care*, N. Engl. J. Med. 2020, 383: e16 (2020), <https://www.nejm.org/doi/10.1056/NEJMp2011359>; B. Tolchin *et al.*, *Racial Disparities in the SOFA Score Among Patients Hospitalized with COVID-19*, PLoS ONE 16(9): e0257608 (2021),

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0257608><https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0257608><https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0257608>

(given current unequal patterns in social determinants of health, US crisis standards of care utilizing the SOFA score to allocate medical resources would be more likely to deny these resources to Non-Hispanic Black patients);

S. Roy *et al.*, *The Potential Impact of Triage Protocols on Racial Disparities in Clinical Outcomes Among COVID-Positive Patients in a Large Healthcare System*. PLoS ONE 16(9): e0256763 (2021),

<https://doi.org/10.1371/journal.pone.0256763> <https://doi.org/10.1371/journal.pone.0256763>

<https://doi.org/10.1371/journal.pone.0256763> (concluding that the use of SOFA scores to allocate resources has the potential to exacerbate racial inequities by disproportionately denying care to Black patients and should not be



---

used to determine access to care), Joseph Stramondo, *COVID-19 Triage and Disability: What Not to Do*, Bioethics.net (March 30, 2020), <https://bioethicstoday.org/blog/covid-19-triage-and-disability-what-not-to-do/>.

<sup>12</sup> See NPRM at 63,409-63,410 and accompanying footnotes.

<sup>13</sup> See NAT'L COUNCIL ON DISABILITY, *Quality-Adjusted Life Years and the Devaluation of Life with Disability*, at 45-46 (November 6, 2019), [https://ncd.gov/sites/default/files/NCD\\_Quality\\_Adjusted\\_Life\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf).

<sup>14</sup> See Greg Phyllip Roggin, *The "Oregon Plan" and the ADA: Toward Reconciliation*, 45 J. URBAN & CONTEMPORARY LAW 219 (1994) (noting that a slightly altered version of this prioritized list that addressed some of the concerns about disability discrimination was later approved); Oregon Health Evidence Review Comm'n (HERC), *HERC Use of Quality Adjusted Life Years*, (last visited Oct. 25, 2023), <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Background-HERC%20QALY%20policy.pdf> (noting that the state's Health Evidence Review Commission, which manages the list, still uses QALYs in a limited fashion).

<sup>15</sup> See *id.* at 36-37.

<sup>16</sup> NPRM at 63,410.

<sup>17</sup> See NCD 2019 report, *supra* note 10, at 61-62.

<sup>18</sup> See *id.* at 61.

<sup>19</sup> *Id.*

<sup>20</sup> NAT'L COUNCIL ON DISABILITY, *Alternatives to QALY-Based Cost-Effectiveness Analysis for Determining the Value of Prescription Drugs and Other Health Interventions*, (Nov. 28, 2022).

<https://ncd.gov/publications/2022/alternatives-qaly>.

<sup>21</sup> Josh J. Carlson, *et al.*, *Alternative Approaches to Quality-Adjusted Life-Year Estimation Within Standard Cost-Effectiveness Models: Literature Review, Feasibility Assessment, and Impact Evaluation*, 23 VALUE IN HEALTH 1523-33 (2020); OREGON HEALTH EVIDENCE REVIEW COMMISSION, *HERC Use of Quality Adjusted Life Years*, (2022) <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Background-HERC%20QALY%20policy.pdf>.

<sup>22</sup> Peter J. Neumann & Dan Greenberg, *Is the United States Ready for QALYs?*, 28 Health Affairs 1366 (2009).

<sup>23</sup> See, e.g., U.S. Dep't Health & Hum. Servs., U.S. Dep't of Justice, *Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act* (2015), <https://www.hhs.gov/sites/default/files/disability.pdf><https://www.hhs.gov/sites/default/files/disability.pdf><https://www.hhs.gov/sites/default/files/disability.pdf>; U.S. Dep't of Health & Hum. Servs., U.S. Dep't of Justice, *Settlement between the U.S. Departments of Justice and U.S. Dep't of Health & Hum. Servs. and Massachusetts Department of Children and Families* (Nov. 19, 2020), [https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html)[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html)[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html).

<sup>24</sup> See U.S. Comm'n on Civil Rights, *The Multiethnic Placement Act: Minorities in Foster Care and Adoption* (July 2010), available: [https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal\\_07-01-10.pdf](https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal_07-01-10.pdf)[https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal\\_07-01-10.pdf](https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal_07-01-10.pdf)[https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal\\_07-01-10.pdf](https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal_07-01-10.pdf).

<sup>25</sup> See, e.g., U.S. Dep't of Health & Human Servs., Admin. for Children & Families, Children's Bureau, Child Welfare Info. Gateway, *Disproportionality Data*, <https://www.childwelfare.gov/topics/systemwide/cultural/disproportionality/data/> (last visited Nov. 6, 2023).

<sup>26</sup> 28 C.F.R. § 35.130(d).

<sup>27</sup> "Home and community-based services" as used here are defined consistent with the American Rescue Plan Act to include any of the following: home health care; personal care; PACE; home and community-based services authorized under Social Security Act section 1915(b), (c), (i), (j), and (k); case management; rehabilitative services, including those related to behavioral health, described in Social Security Act section 1905(a)(19), and such other services specified by the Secretary of Health and Human Services. See [American Rescue Plan Act of 2021](#), Pub. L. 117-2 § 9817(a)(2)(B).

<sup>28</sup> We note that "evidence-based" is intended to apply to parenting evaluations, and should not be applied to determining whether an individual needs reasonable modifications or accommodations.

<sup>29</sup> See proposed 45 CFR 84.68(b)(7).

<sup>30</sup> Even if children with disabilities are not segregated from children without disabilities in an institutional setting, the institutional placement is still considered a segregated setting. *G.K. v. Sununu*, No. 21-cv-4-PB, 2021 U.S. Dist. LEXIS 170962 (D.N.H. 2021)

---

31 In Florida, children are hospitalized under involuntary commitment orders (“Baker Act”) when they are not provided sufficient behavioral services at school or at home and there is no appropriate placement for them. Once in the system, it is difficult to leave.

32 Many of the residential placements used by child welfare agencies are neither safe nor therapeutic. For more information about this issue, please see National Disability Rights Network, *Desperation without Dignity: Conditions of Children Placed in For Profit Residential Facilities* (2021), available: <https://www.ndrn.org/resource/desperation-without-dignity/>

33 See, e.g., United States Dep’t of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *Mental Health: A Report of the Surgeon General*, at 176–178 (1999), available at <http://download.ncadi.samhsa.gov/ken/pdf/surgeongeneralreport/C3.pdf>; Richard P. Barth, *Institutions vs. Foster Homes: An Empirical Base for a Century of Action*, University of North Carolina at Chapel Hill, School of Social Work, at 7 (June 17, 2002); National Council on Disability, *Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions* (2008), available: <https://www.ncd.gov/publications/2008/02262008>.<https://www.ncd.gov/publications/2008/02262008>.

34 Use of the term “child” should be read to include both children and youth. Youth with disabilities in the child welfare system have unique and specific needs and are more likely to be placed in a segregated setting and have poorer permanency outcomes than their younger peers.

35 Am. Bar Assoc., *Trauma Caused by Separation of Children from Parents* (americanbar.org) (2019), available: <https://www.americanbar.org/groups/litigation/about/committees/childrens-rights/trauma-child-parent-separation/>

36 See Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (2012), [https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf)[https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf)[https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf); Child Welfare Information Gateway, *Reasonable Efforts to Preserve or Reunify Families and Achieve Permanency for Children* (2019), available: <https://www.childwelfare.gov/pubpdfs/reunify.pdf><https://www.childwelfare.gov/pubpdfs/reunify.pdf><https://www.childwelfare.gov/pubpdfs/reunify.pdf>

37 U.S. Dep’t Health & Hum. Servs., U.S. Dep’t of Justice, *Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act* (2015), <https://www.hhs.gov/sites/default/files/disability.pdf>.<https://www.hhs.gov/sites/default/files/disability.pdf><https://www.hhs.gov/sites/default/files/disability.pdf>

38 U.S. Dep’t of Health & Hum. Servs., U.S. Dep’t of Justice, *Settlement between the U.S. Departments of Justice and U.S. Dep’t of Health & Hum. Servs. and Massachusetts Department of Children and Families* (Nov. 19, 2020), [https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html).[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html)[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html)

39 Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (2012), [https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf).[https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf)[https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf)

40 See, e.g., *Katie A. v. Bonta*, 433 F. Supp. 2d 1065 (C.D. Cal. 2006)

41 *U.S. v. Florida*, No. 12-cv-60460-MIDDLEBROOKS/Hunt, 2023 U.S. Dist. LEXIS 121655 (S.D. Fla. July 14, 2023).

42 See, e.g., Cindy Mann & Pamela S. Hyde, Joint CMCS and SAMHSA Informational Bulletin: Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions, Substance Abuse and Mental Health Servs. Admin. (SAMHSA) and Center for Medicaid and CHIP Services (CMCS), 5 (2013) (“Joint SAMHSA/CMCS Bulletin”), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf>.

43 National Disability Rights Network, About, <https://www.ndrn.org/about/><https://www.ndrn.org/about/><https://www.ndrn.org/about/> (Last visited Oct. 27, 2023).

44 We add here only content that has not be addressed above in this comment.

---

45 See, e.g., U.S. Dep't of Health & Hum. Servs., U.S. Dep't of Justice, *Settlement between the U.S. Departments of Justice and U.S. Dep't of Health & Hum. Servs. and Massachusetts Department of Children and Families* (Nov. 19, 2020), [https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html).[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html)[https://archive.ada.gov/mdcf\\_sa.html](https://archive.ada.gov/mdcf_sa.html).

<sup>46</sup> As used throughout this comment, “home and community-based services” or HCBS are defined as in the American Rescue Plan Act to include any of the following: home health care; personal care; PACE; home and community-based services authorized under Social Security Act section 1915(b), (c), (i), (j), and (k); case management; rehabilitative services, including those related to behavioral health, described in Social Security Act section 1905(a)(19), and such other services specified by the Secretary of Health and Human Services.

See [American Rescue Plan Act of 2021](#), Pub. L. 117–2 § 9817(a)(2)(B).

<sup>47</sup> American Council of the Blind (Press Release, October 25, 2023). American Council of the Blind (ACB) Wins Nationwide Disability Rights Class Action Against Quest Diagnostics for Use of Inaccessible Touch Screen Kiosks. <https://www.prnewswire.com/news-releases/american-council-of-the-blind-acb-wins-nationwide-disability-rights-class-action-against-quest-diagnostics-for-use-of-inaccessible-touch-screen-kiosks-301966895.html>

<sup>48</sup> See Caffia (March 30, 2023). Contactless Payment Coffee Machine. <https://caffia.com/contactless-payment-coffee-machine/>

<sup>49</sup> W3C (24 September 2015). Authoring Tool Accessibility Guidelines (ATAG) 2.0. <https://www.w3.org/TR/ATAG20/>

<sup>50</sup> W3C (15 December 2015). User Agent Accessibility Guidelines (UAAG) 2.0. <https://www.w3.org/TR/UAAG20/>

<sup>51</sup> See Utah Department of Health and Human Services (@UTAHDHHS), X (Oct, 19, 2023), <https://twitter.com/UtahDHHS/status/1715081505007923492> (State health departments share information on getting vaccines and staying well via videos.)

<sup>52</sup> See Children’s National Hospital (@ChildrensNatl), X (Oct 16, 2023), <https://twitter.com/ChildrensNatl/status/1713940125938315611> (Hospitals provide videos and links to help patients learn about new ways of accessing information and care.)

<sup>53</sup> See South Central Community Action (@insscap), Instagram (May 4, 2023), <https://www.instagram.com/insscap/?hl=en> (Human services providers post images displaying upcoming deadlines and information about programs.)

<sup>54</sup> See Epic Systems Corporation. MyChart. Google Play. <https://play.google.com/store/apps/details?id=epic.mychart.android>

<sup>55</sup> AliveCor, Inc. Kardia. App Store. <https://apps.apple.com/us/app/kardia/id579769143> (“Kardia works with the FDA-cleared KardiaMobile, KardiaMobile 6L, or KardiaBand personal EKG devices, which can detect the most common arrhythmias in just 30 seconds. The Kardia app is designed to make managing heart care from home easier than ever, giving you the ability to seamlessly record EKGs, share heart data with your doctor remotely, keep track of your health history, and more.”)

<sup>56</sup> UnitedHealthcare (February 20, 2019). UnitedHealthcare Helps People Manage Chronic Conditions through Data-Powered Nerve Center as Navigate4Me Program Expands. <https://www.unitedhealthgroup.com/newsroom/2019/2019-02-20-uhc-navigate4me-chronic-conditions.html>

<sup>57</sup> Consortium for Constituents with Disabilities and other disability organizations (October 3, 2023). Comments in response to DOJ-CRT-2023-0007, Nondiscrimination on the Basis of Disability; Accessibility of Web Information and Services of State and Local Government Entities. <https://www.regulations.gov/comment/DOJ-CRT-2023-0007-0293>

<sup>58</sup> <https://hms.harvard.edu/news-events/publications-archive>

<sup>59</sup> See California Department of Public Health (Updated May 23, 2018). California conference of local health officers Semiannual Meetings. <https://www.cdph.ca.gov/Programs/CCLHO/Pages/SemiannualMeetings.aspx>

<sup>60</sup> See Georgia DNR Wildlife (@GeorgiaWild), X (Nov. 15, 2022), <https://twitter.com/GeorgiaWild/status/1592509698414374912> (State and local governments share safety information on social media, such as this warning about bears. Public commentary on posts like this sometimes provides further warnings about bear sightings and activity in specific places.); see also *Getting Social During a Disaster*, General Code (last visited Sept. 11, 2023, 6:11 PM), <https://www.generalcode.com/blog/getting-social-during-a-disaster/>.

<sup>61</sup> See Andy Castillo, Social media can play an important role in a community’s emergency response, American City and County (Oct. 1, 2021), <https://www.americancityandcounty.com/2021/10/01/social-media-can-play-an-important-role-in-a-communitys-emergency-response/> (An article on a website for city and county governments CCD Joint Task Force HHS 504 Comments, Docket No: 2023-19149

---

describes using social media to share updates in real time in disaster situations and coordinate professional and volunteer emergency response); see also Dionne Mitcham, Morgan Taylor, and Curtis Harris, *Utilizing Social Media for Information Dispersal during Local Disasters: The Communication Hub Framework for Local Emergency Management*, 18 Int'l. Journal of Env'tl. Research and Public Health 20, 10784 (2021).

<sup>62</sup> See Barbara D (@Menopausalins01), X (Aug. 25, 2023), <https://twitter.com/Menopausalins01/status/1694964254799978808>, (A person replied to a tweet by the governor of New Jersey, saying "...I keep asking @GovMurphy why he wants to contribute to breweries closing, increased unemployment, & lost revenue to surrounding businesses by not signing bipartisan-passed bill 3038/4630..."); see also City of Monterey, California (@cityofmonterey), Instagram (Aug. 8, 2023), <https://www.instagram.com/p/CvsnUtMymFx/> (A third party who self-identifies as disabled left a comment on this Instagram post complaining about parking enforcement in the city.); Schenectady Police Department (Schenectady Police Department), Facebook (July 19, 2023), <https://www.facebook.com/photo/?fbid=606649371572185&set=a.267037512200041> (Two different discussions by private persons- one on opioid use and narcans, the other on police conduct- transpired in the comments on a Facebook post by the local police in Schenectady, New York).

<sup>63</sup> See Atlanta Department of Procurement (@atlprocurement), Instagram (last visited Sept. 11, 2023, 10:28 PM), <https://www.instagram.com/atlprocurement/> (Atlanta, Georgia has an Instagram account for its procurement department that shares information about contracting opportunities); see also Smithfield North Carolina (Town of Smithfield, NC Government), Facebook (Aug. 25, 2023), <https://www.facebook.com/photo/?fbid=691995036292051&set=a.225523152939244> (When a small town in North Carolina announced a public meeting, two other parties asked questions relevant to public involvement in the comments); Decatur, Georgia (City of Decatur GA- Government), Facebook (June 20, 2023) (Decatur announced a planning meeting to discuss changes to an important, local thoroughfare. Members of the public brought up concerns and complaints in the comments), <https://www.facebook.com/photo/?fbid=637440421744748&set=a.230709499084511>.

<sup>64</sup> See The State Bar of California, *Public Comment Archives* (last visited Sept. 12, 2023, 4:00 PM), <https://www.calbar.ca.gov/About-Us/Our-Mission/Protecting-the-Public/Public-Comment/Public-Comment-Archives/2023-Public-Comment>.

<sup>65</sup> See Poll Everywhere, Create a word cloud with the audience, <https://www.pollerywhere.com/word-cloud> ("When you create a word cloud using Poll Everywhere, each word comes from the audience. You ask the question, the audience responds on their phones, and together you see opinions become artwork. Words move and grow with each new response.")

<sup>66</sup> See City of Dallas, *Past Public Opportunities*, Procurement Portal (last visited Sept. 12, 3:05 PM), <https://dallascityhall.bonfirehub.com/portal/?tab=pastOpportunities> (Third party uploads on successful contracts might be very helpful to an aspiring public contractor. If these are inaccessible, this learning opportunity and the prospect of financial benefit might be off limits to some members of the disability community).

<sup>67</sup> See Mitchell Clark, *Twitter is testing changes to make image descriptions easier to access*, The Verge (Mar. 9, 2022), <https://www.theverge.com/2022/3/9/22969304/twitter-image-description-alt-text-test-accessibility>; see also Meg Miller and Ilaria Parogni, *The Hidden Image Descriptions Making the Internet Accessible*, The New York Times (Feb. 18, 2022), <https://www.nytimes.com/interactive/2022/02/18/arts/alt-text-images-descriptions.html>.

<sup>68</sup> See Issaquah, Washington (cityofissaquah), Instagram (June 2, 2023), [https://www.instagram.com/p/CtAiX73pkCr/?img\\_index=1](https://www.instagram.com/p/CtAiX73pkCr/?img_index=1) (Issaquah, Washington marked Pride Month on its Instagram account. Community members discussed the recognition of other times of significance in the comments.); see also City of Hallandale Beach, Florida (myhbeach), Instagram (last visited Sept. 12, 2023, 10:17 AM), <https://www.instagram.com/p/Cw48UzBO1iX/> (Hallandale Beach puts everything from dog park closures to community events to reminders about tax-free back-to-school shopping to recognition of National Suicide Prevention Week on its Instagram account. Third parties have used the comments to publicly respond to some posts); Brent Barnhart, *Social media and government: how to keep citizens engaged*, Sprout Social (Jan. 13, 2022), <https://sproutsocial.com/insights/social-media-and-government/> (This blog post provides guidance to state and local governments on how to promote online community engagement regarding important issues).

<sup>69</sup> See Northeastern Ohio Regional Sewer District (@neorsd), X (last visited Sept. 12, 2023, 1:46 PM), <https://twitter.com/neorsd> (This active sewer district X account engages back and forth with individuals but also entities that may be covered by Title III.).

- 
- <sup>70</sup> See City of Chicago (City of Chicago- Government), Facebook (Aug. 19, 2023), <https://www.facebook.com/photo?fbid=620041563647012&set=a.420537146930789> (Chicago posted information on Facebook on disaster recovery for both residents and business owners. As of writing, the discussion on the post has been individual and political, but this is the kind of forum in which people working on behalf of entities covered by Titles I and III might
- <sup>71</sup> See *Robles v. Domino's Pizza, LLC*, 913 F.3d 898 (9th Cir. 2019); see also United States Dep't. of Justice, Guidance on Web Accessibility and the ADA (Mar. 18, 2022), <https://www.justice.gov/opa/pr/justice-department-issues-web-accessibility-guidance-under-americans-disabilities-act>.
- <sup>72</sup> Unpublished data from Rhoads, C.R., Bleach, K., Chatfield, S. & Camarilla, P. (2022). The Journey Forward: Impact of COVID-19 on Blind, Low Vision, and Deafblind U.S. Adults. American Foundation for the Blind. [www.afb.org/JF](http://www.afb.org/JF)
- <sup>73</sup> 42 U.S.C. § 12132; 28 C.F.R. § 35.130(b)(1)(i) and (2).
- <sup>74</sup> See: U.S. DOJ Consent Decree with University of California, Berkeley and ...more than 1,000 cases in recent years related to digital access that were triggered by complaints of discrimination by members of the public. These agreements address the accessibility of public-facing websites, learning management systems, password-protected student-facing content, and mass email blasts of colleges, universities, and other postsecondary institutions (pg. 2), *Joint U.S. Department of Education and U.S. Department of Justice Dear Colleague Letter on Online Accessibility at Postsecondary Institutions May 19, 2023* [https://www.justice.gov/d9/case-documents/attachments/2023/05/19/letter-dear\\_colleague.pdf](https://www.justice.gov/d9/case-documents/attachments/2023/05/19/letter-dear_colleague.pdf)
- <sup>75</sup> See: National Center on Accessible Educational Materials (2020). Higher Education Critical Components of the Quality Indicators for the Provision of Accessible Educational Materials Accessible Technologies. Wakefield, MA: National Center on Accessible Educational Materials at: <https://aem.cast.org/get-started/resources/2020/higher-education-critical-components-of-the-quality-indicators-for-the-provision-of-accessible-educational-materials-accessible-technologies>
- <sup>76</sup> See: 84 FR 56154 which interprets “print instructional materials” in section 674(e)(3)(C) of IDEA ([20 U.S.C. 1474\(e\)\(3\)\(C\)](https://www.federalregister.gov/documents/2019/04/24/2019-08443-idea)) to include digital instructional materials.
- <sup>77</sup> See: National Center on Accessible Educational Materials (2020). AEM Quality Indicators with Critical Components for K–12. Wakefield, MA: National Center on Accessible Educational Materials, at: <https://aem.cast.org/binaries/content/assets/common/publications/aem/k12-aem-qualityindicators-criticalcomponents.pdf>
- <sup>78</sup> 34 C.F.R. § 300.324(a)(2)(iv) and (v)
- <sup>79</sup> American Foundation for the Blind, *Access and Engagement II*, Research Report (May 2021) at 64.
- <sup>80</sup> Silverman, A., Bleach, K., Mungia Rodriguez, G., Rhoads, C. & Hernandez Legorreta, C. (2022). Access and Engagement III: An Extended Examination of the Impact of the COVID-19 Pandemic on Students with Visual Impairments, Their Families, and Professionals. American Foundation for the Blind. <https://www.afb.org/research-and-initiatives/education/covid19-education-research/access-and-engagement-iii/access>
- <sup>81</sup> American Foundation for the Blind, *Access and Engagement II*, Research Report (May 2021) at 64.
- <sup>82</sup> Lauraine Langreo, “[What Teachers Really Think About Their Learning Management Systems](#),” EdWeek (Sept. 21, 2022)
- <sup>83</sup> See also Imed Bouchrika, Phd, “[5 Top College Trends on LMS Use by Universities in 2023](#),” Research.com (2020).
- <sup>84</sup> Mythili Sampathkumar and Maya Shwayder, “[The Mass Migration to Online Learning Is Leaving Disabled Students Behind](#),” Digital Trends (Mar. 27, 2020).
- <sup>85</sup> See: Creating Accessible Websites at: <https://aem.cast.org/create/creating-accessible-websites>
- <sup>86</sup> National Council on Disability, *Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* (May 20, 2021), available at [https://ncd.gov/sites/default/files/Documents/NCD\\_Medical\\_Equipment\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/Documents/NCD_Medical_Equipment_Report_508.pdf).
- <sup>87</sup> 82 FR 2810, 2815 (Jan. 9, 2017).
- <sup>88</sup> See *U.S. v. Barnett Dulaney Perkins Eye Center, PC, and Medical Management Resources Group, L.L.C.*, No. 21-cv-2172-PHX-SRB (Jan. 17, 2023), available at <https://www.justice.gov/media/1268741/dl?inline>.
- <sup>89</sup> Centers for Disease Control and Prevention, *Disabilities Impact Us All* (May 2023), <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.
- <sup>90</sup> U.S. Census Bureau, *National Senior Citizens Day* (Aug. 21, 2022), available at <https://www.census.gov/newsroom/stories/senior-citizens-day.html>.

- 
- <sup>91</sup> U. S. Census Bureau, “Week 60 Household Pulse Survey: July 26 – August 7,” August 16, 2023, available at <https://www.census.gov/data/tables/2023/demo/hhp/hhp60.html>.
- <sup>92</sup> U.S. Census Bureau, Living With Disabilities (Sept. 30, 2021), available at <https://www.census.gov/library/visualizations/2021/comm/living-with-disabilities.html>.
- <sup>93</sup> National Institute on Disability and Rehabilitation Research, U.S. Department of Education, Mobility Device Use in the United States, Disabled World (April 22, 2013), available at <https://www.disabled-world.com/disability/statistics/mobility-stats.php><https://www.disabled-world.com/disability/statistics/mobility-stats.php>. (Note: although the exact number of wheelchair users may be different now versus an older report, the study does show the difference in mobility device users among age groups. The number and percentage of specific device users should not be derived from this report due to changes in the availability of such devices in the past decade).
- <sup>94</sup> See 49 C.F.R. §§ 37 – 39.
- <sup>95</sup> 49 C.F.R. § 37 Subtit. D, E.
- <sup>96</sup> Steer Davies Gleave, U.K. Dep’t for Transport, Access for All Benefit Research: Impacts of Station Accessibility Improvements 62 (2015), <https://uk.steergroup.com/sites/default/files/2021-03/Access4AllBenefitResearch2015.pdf#page=10>.
- <sup>97</sup> Department of Justice, Civil Rights Division, 28 CFR Part 36, RIN 1190–AA44 Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, Final Rule, Supplementary Information, Additional Benefits of Water Closet Clearance Standards.
- <sup>98</sup> Department of Health & Human Services, Centers for Medicare & Medicaid Services, Office of Clinical Standards and Quality/Survey & Certification Group (Dec. 2011), [https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/SCLetter12\\_07.pdf](https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/SCLetter12_07.pdf).
- <sup>99</sup> See 28 CFR 35.130(f) (“A public entity may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility, that are required to provide that individual or group with the nondiscriminatory treatment required by the Act or this part.”).
- <sup>100</sup> Carol K. Kane, Recent Changes in Physician Practice Arrangements: Private Practice Dropped to Less Than 50 Percent of Physicians in 2020, Policy Research Perspectives, American Medical Association (2021), <https://www.ama-assn.org/system/files/2021-05/2020-prp-physician-practice-arrangements.pdf>.
- <sup>101</sup> See U.S. v. Barnet Dulaney Perkins Eye Center, PC, Consent Decree.
- <sup>102</sup> See 28 CFR 35.130(f) (“A public entity may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility, that are required to provide that individual or group with the nondiscriminatory treatment required by the Act or this part.”).
- <sup>103</sup> See U.S. v. Barnet Dulaney Perkins Eye Center, PC, Consent Decree.
- <sup>104</sup> See 28 CFR 35.130(f) (“A public entity may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility, that are required to provide that individual or group with the nondiscriminatory treatment required by the Act or this part.”).
- <sup>105</sup> See Whitney J. Palmer, Leasing Medical Equipment: A Viable Option for Private Practice, WOLTERS KLUWER (2020), <https://www.wolterskluwer.com/en/expert-insights/leasing-medical-equipment-a-viable-option-for-private-practice>.
- <sup>106</sup> Department of Justice, Civil Rights Division, 28 CFR Part 36, RIN 1190–AA44 Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, Final Rule, Supplementary Information, Additional Benefits of Water Closet Clearance Standards.
- <sup>107</sup> Medical Device Nonvisual Accessibility Act of 2023, H.R. 1328, 118th Cong. (2023), <https://www.congress.gov/bill/118th-congress/house-bill/1328/text?s=1&r=80&q=%7B%22search%22%3A%5B%22H.R.+6%22%5D%7D>.
- <sup>108</sup> Occupational Safety and Health Administration, Facts about Hospital Worker Safety (Sept. 2013), [https://www.osha.gov/sites/default/files/1.2\\_Factbook\\_508.pdf](https://www.osha.gov/sites/default/files/1.2_Factbook_508.pdf).
- <sup>109</sup> See Department of Health & Human Services, Centers for Medicare & Medicaid Services, Office of Clinical Standards and Quality/Survey & Certification Group (Dec. 2011), [https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/SCLetter12\\_07.pdf](https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/SCLetter12_07.pdf).
- CCD Joint Task Force HHS 504 Comments, Docket No: 2023-19149

---

<sup>110</sup> U.S. Dep’t of Justice, DOJ Policy Statement: Reasonable Accommodation (Sept. 2019), available at <https://www.justice.gov/jmd/page/file/1212826/download> (p. 4).

<sup>111</sup> **28 CFR § 35.130(h)**: A public entity may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities. However, the public entity must ensure that its safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities.

<sup>112</sup> **28 CFR § 35.139** “(a) This part does not require a public entity to permit an individual to participate in or benefit from the services, programs, or activities of that public entity when that individual poses a direct threat to the health or safety of others. (b) In determining whether an individual poses a direct threat to the health or safety of others, a public entity must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk.” (emphasis added).

<sup>113</sup> Community Integration for People with Disabilities: Key Principles (2014), available at <https://www.bazelon.org/wp-content/uploads/2017/10/Key-Principles.pdf> (“Individuals with disabilities should have the opportunity to live like people without disabilities”). See also U.S. Dep’t of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, Question 1 (2020), <https://www.ada.gov/resources/olmstead-mandate-statement/> (last visited Oct. 25, 2023) (“integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities”); and U.S. Dep’t of Housing and Urban Development, Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of *Olmstead* (2013), available at <https://www.hud.gov/sites/documents/OLMSTEADGUIDNC060413.PDF> (“within the context of housing, integrated settings enable individuals with disabilities to live like individuals without disabilities”), and Bazelon Center for Mental Health Law, *Making Your Life Your Own: How Olmstead Expands Rights and Opportunities for People with Serious Mental Illnesses* (2011), available at <https://www.bazelon.org/wp-content/uploads/2017/08/Making-Your-Life-Your-Own-White-Paper-Format.pdf>.

<sup>114</sup> See U.S. Dep’t of Justice, Frequently Asked Questions about Service Animals and the ADA, Question 4 (2020), available at <https://www.ada.gov/resources/service-animals-faqs/> (last visited Oct. 25, 2023). See also U.S. Dep’t of Justice, Service Animals: Examples of Service Animal Tasks, available at <https://www.ada.gov/topics/service-animals/#examples-of-service-animal-tasks> (last visited Oct. 25, 2023).

<sup>115</sup> U.S. Access Board, Americans With Disabilities Act Accessibility Guidelines for Buildings and Facilities; Architectural Barriers Act Accessibility Guidelines; Self-Service Transaction Machines and Self-Service Kiosks, RIN: 3014-AA44 (Sept. 21, 2021), <https://www.federalregister.gov/documents/2022/09/21/2022-20470/americans-with-disabilities-act-accessibility-guidelines-for-buildings-and-facilities-architectural>.

<sup>116</sup> 28 CFR 35.150(a)(3).

<sup>117</sup> See CCD Comments, B.1.1.3 “Most Integrated Setting” (§ 84.10).

<sup>118</sup> See *U.S. v. Barnet Dulaney Perkins Eye Center, PC, and Medical Management Resources Group, L.L.C.*, No. 21-cv-2172-PHX-SRB (Jan. 17, 2023), available at <https://www.justice.gov/media/1268741/dl?inline>.

<sup>119</sup> See 28 CFR 35.130(f) (“A public entity may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility, that are required to provide that individual or group with the nondiscriminatory treatment required by the Act or this part.”).

<sup>120</sup> See: Consortium for Constituents with Disabilities Letter to U.S. Congress, November 19, 2021.

<sup>121</sup> In 2019, children living in poverty were more likely to have a disability (6.5%) than children living above the poverty threshold (3.8%). The difference in the prevalence of disability between children below and above the poverty threshold is noteworthy. <https://www.census.gov/library/stories/2021/03/united-states-childhood-disability-rate-up-in-2019-from-2008.html>

<sup>122</sup> *The Child Care Crisis Disproportionately Affects Children With Disabilities*, Center for American Progress, (2020). <https://www.americanprogress.org/article/child-care-crisis-disproportionately-affects-children-disabilities/>

<sup>123</sup> *Ibid.*

<sup>124</sup> See NPRM at 63,474 – 63,475.

<sup>125</sup> *Id.* at 63,474.

CCD Joint Task Force HHS 504 Comments, Docket No: 2023-19149

---

126 See Undersigned Members of the Consortium for Constituents with Disabilities, *Statement for the Written Record of the U.S. Senate Special Committee on Aging’s Hearing on Guardianship, Conservatorships, Protective Arrangements, and Alternatives*, at 3 and n.9 (March 30, 2023), [https://www.c-c-d.org/fichiers/CCD-Rights-Statement-on-Guardianship-and-Alternatives-\(submitted-03.23.2023\).pdf](https://www.c-c-d.org/fichiers/CCD-Rights-Statement-on-Guardianship-and-Alternatives-(submitted-03.23.2023).pdf).

127 See Summit Delegates, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability - Recommendations Adopted by Summit Delegates*, 72 SYRACUSE L. REV. 29, 34 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/09/29-40-Preface-2.pdf> (recommending that SDM be recognized as a possible “reasonable accommodation under the Americans with Disabilities Act of 1990, as amended, in supporting an individual in making their own decisions and retaining their right to do so”)

128 See NPRM at 63,474 – 63,475 and n.481 (citing UGCOPAA Sec. 102(31)).

129 *Id.* at 63,475.

130 See Morgan K. Whitlatch & Rebekah Diller, *Supported Decision-Making: Potential and Challenges for Older Persons*, 72 SYRACUSE L. REV. 165, 193-196 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/10/5.-Whitlatch-Diller.pdf> (discussing the link between SDM and accommodating older adults with disabilities requiring in-person supporters in this context).

<sup>131</sup> 28 CFR § 35.136. 28 CFR § 35.136; *see also* 28 C.F.R. pt. 35, app. A § 35.136 (2018) (explaining that new provisions were added to the Title II 2010 regulations to align with the Title III 1991 regulations and to clarify the existing obligation of covered entities to make reasonable modifications to allow service animals).

<sup>132</sup> *See, e.g.*, 28 C.F.R. § 35.136(d) “[a] service animal shall have a harness, leash, or other tether, unless either the handler is unable because of a disability”; 28 C.F.R. pt. 35, app. A § 35.136 (2018) (“...the work or tasks performed by the service animal must be directly related to the handler’s disability”; and referring to the service dog providing services to the animal’s handler, thus implying the handler is the person with a disability). *See also* U.S. Dep’t of Justice, Memorandum of Law in Support of Mot. For Summary Judgment, [https://archive.ada.gov/gateschili/gateschili\\_msj.html](https://archive.ada.gov/gateschili/gateschili_msj.html) (“As this Court previously found and the District agreed, the Title II regulation clearly contemplates that the person with a disability is typically the handler of their own service dog.”).

<sup>133</sup> A person with a disability and her service animal function as a unit such that separating the two generally is discriminatory under the ADA. *See Alboniga v. Sch. Bd. Broward Cty. Fla.*, 87 F. Supp. 3d 1319, 1341 (S.D. Fla. 2015) (citations omitted).

<sup>134</sup> *See* 28 C.F.R. § 35.136(d).

<sup>135</sup> *See Alboniga v. Sch. Bd. Broward Cty. Fla.*, 87 F. Supp. 3d 1319, 1342 (S.D. Fla. 2015) (finding that “[t]he complete language of the regulatory provision . . . explicitly permits tethering as handling”); *Riley v. Sch. Admin. Unit #23*, No. 15-CV-152-SM, 2015 WL 9806795, at \*9-10 (D.N.H. Dec. 22, 2015) (holding that tethering constitutes control under § 35.136 and quoting *Alboniga*).

<sup>136</sup> *Alboniga*, 87 F. Supp. 3d at 1342 (“[N]ormally, tethering a service animal to the wheelchair of a disabled person constitutes ‘control’ over the animal by the disabled person, acting as the animal’s ‘handler.’”).

<sup>137</sup> *Id.* at 1323, 1341-42.

<sup>138</sup> *See* 28 C.F.R. § 35.136(d) (where tethering is not possible, “the service animal must be otherwise under the handler’s control (*e.g.*, voice control, signals, or other effective means)”; *Alboniga*, 87 F. Supp. 3d at 1342; *Riley v. Sch. Admin. Unit #23*, No. 15-CV-152-SM, 2015 WL 9806795, at \*9-10 (D.N.H. Dec. 22, 2015).

<sup>139</sup> *See* U.S. Dep’t of Justice, Reply Memorandum in Support of United States’ Mot. For Summary Judgment, [https://archive.ada.gov/gateschili/gateschili\\_reply.html](https://archive.ada.gov/gateschili/gateschili_reply.html).

<sup>140</sup> The importance of a service dog team and the harms of separation have also been recognized by courts and Congress. *See Tamara v. El Camino Hosp.*, 964 F. Supp. 2d 1077, 1087 (N.D. Cal. 2013) (finding that separating an individual from his service animal can cause irreparable harm and deprive that individual of independence); *Lentini v. California Ctr. for the Arts, Escondido*, 370 F.3d 837, 845 (9th Cir. 2004) (public accommodation was required to modify its policies by admitting plaintiff’s service animal; in part due to human-dog bond, modification was “necessary” even though plaintiff could be “accompanied by an able-bodied companion, and even though the defendant offered the assistance of specially-trained staff”); 135 Cong. Rec. S.10,800 (1989) (statement of Sen. Simon) (“[a] person with a disability and his . . . [service] animal function as a unit” such that separating the two generally “[is] discriminatory under the [ADA]”).

<sup>141</sup> 28 C.F.R. pt. 35, app. A § 35.136 at 629 (2018). *See Alboniga*, 87 F. Supp. 3d at 1343-44; *Shields v. Walt Disney Parks & Resorts US, Inc.*, 279 F.R.D. 529, 548 (C.D. Cal. 2011); *McDonald v. Dep’t of Env’tl. Quality*, 351 Mont. 243, CCD Joint Task Force HHS 504 Comments, Docket No: 2023-19149



---

264 (Mont. 2009) (explaining, for example, “you cannot ask the ticket-taker to watch your dog for you while you go in and watch the movie”).

<sup>142</sup> 28 C.F.R. pt. 36, app. C § 36.302 at 967 (2018).

<sup>143</sup> See, e.g., *C. By & Through Ciriacks v. Cypress Sch. Dist.*, No. SACV11352AGMLGX, 2011 WL 13130855, at \*1, 6 (C.D. Cal. June 13, 2011); *Alboniga*, 87 F. Supp. 3d at 1341-42, 1344-45.

<sup>144</sup> See U.S. Dep’t of Justice, Frequently Asked Questions about Service Animals and the ADA, Question 8 (2020), <https://www.ada.gov/resources/service-animals-faqs/>. See also U.S. Dep’t of Justice, Service Animals: About Service Animals, <https://www.ada.gov/topics/service-animals/#about-service-animals> (last visited Oct. 25, 2023). See also *C.L. v. Del Amo Hosp.*, 992 F.3d 901 (9th Cir. 2021).

<sup>145</sup> See U.S. Dep’t of Justice, Frequently Asked Questions about Service Animals and the ADA, Question 14 (2020), <https://www.ada.gov/resources/service-animals-faqs/> (last visited Oct. 25, 2023).

<sup>146</sup> See 28 CFR § 35.137.

<sup>147</sup> See 28 CFR 35.104, ADA Title II Definitions for “Wheelchair” and “Other Power-Driven Mobility Device”.

<sup>148</sup> See *Wright v. New York State Dep’t of Corr.*, 831 F.3d 64 (2d Cir. 2016) (holding the correctional facilities’ blanket ban on the use of motorized wheelchairs in prison violated the ADA and Rehabilitation Act).

<sup>149</sup> 28 CFR § 35.139(a) (“This part does not require a public entity to permit an individual to participate in or benefit from the services, programs, or activities of that public entity when that individual poses a direct threat to the health or safety of others”).

<sup>150</sup> 28 CFR § 35.130(h) (“A public entity may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities. However, the public entity must ensure that its safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities”).

<sup>151</sup> 28 CFR § 35.139(b) (“In determining whether an individual poses a direct threat to the health or safety of others, a public entity must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk”).

<sup>152</sup> *Leiken v. Squaw Valley Ski Corp.*, No. CIV. S-93-1622 LKK, 1994 WL 494298, (E.D. Cal. June 28, 1994) (certifying a class action under ADA Title III for an entity with a blanket ban against wheelchair users).

<sup>153</sup> *Wright v. New York State Dep’t of Corr.*, 831 F.3d 64 (2d Cir. 2016) (holding that correctional facilities’ blanket ban on the use of motorized wheelchairs in prison violated the ADA and Rehabilitation Act).

<sup>154</sup> *Williams v. A&M Bros, LLC*, No. 122CV00077JLTBAM, 2023 WL 4747481 (E.D. Cal. July 25, 2023) (denying the defendant’s motion to dismiss under ADA Title III after denying entry of a patron who used a walking stick).

<sup>155</sup> U.S. Dep’t of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, Question 1 (2020), <https://www.ada.gov/resources/olmstead-mandate-statement/> (last visited Oct. 25, 2023).

<sup>156</sup> See *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 675 (2001) (Congress enacted the ADA to meet a “‘compelling need’ for a ‘clear and comprehensive national mandate’ to eliminate discrimination against disabled individuals, and to integrate them ‘into the economic and social mainstream of American life’”) (citing S. Rep. No. 101-116, p. 20 (1989); H. R. Rep. No. 101-485, pt. 2, p. 50 (1990)), and National Archives, Transcript of Statement by the President July 26, 1990 (1990), <https://www.archives.gov/research/americans-with-disabilities/transcriptions/naid-6037493-statement-by-the-president-americans-with-disabilities-act-of-1990.html> (last visited Oct. 25, 2023) (the ADA signals the end of the “unjustified segregation and exclusion of persons with disabilities from the mainstream of American life”).

<sup>157</sup> See U.S. Dep’t of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, Question 1 (2020), <https://www.ada.gov/resources/olmstead-mandate-statement/> (last visited Oct. 25, 2023) (“integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities”), and U.S. Dep’t of Housing and Urban Development, Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of *Olmstead* (2013), available at <https://www.hud.gov/sites/documents/OLMSTEADGUIDNCO60413.PDF> (“within the

---

context of housing, integrated settings enable individuals with disabilities to live like individuals without disabilities”).

<sup>158</sup> Community Integration for People with Disabilities: Key Principles (2014), available at <https://www.bazelon.org/wp-content/uploads/2017/10/Key-Principles.pdf> (recognizing that “individuals with disabilities should have the opportunity to live like people without disabilities” and providing examples of community integration in the contexts of employment, housing, choice, and everyday life).

<sup>159</sup> National Council on Disability, Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters (2019), available at <https://ncd.gov/publications/2019/preserving-our-freedom>.

<sup>160</sup> Centers for Medicare & Medicaid Services, COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers, 5 n.1 (2022), available at <https://www.cms.gov/files/document/covid-19-emergency-declaration-waivers.pdf>.

<sup>161</sup> National Council on Disability, Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters, 10 (2019), available at [https://ncd.gov/sites/default/files/NCD\\_Preserving\\_Our\\_Freedom\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Preserving_Our_Freedom_508.pdf).

<sup>162</sup> 42 CFR § 483.21(c); see also F-Tag F660 of Appendix PP of State Operations Manual.

<sup>163</sup> See, e.g., Opening Brief of CVS in *CVS v. Doe*, No. 20-1374 (U.S. Sept. 3, 2021) 10-11 (“The statutory text unambiguously forecloses disparate-impact liability. ... Section 504 requires that the discrimination be ‘solely by reason of’ disability. ... [T]hat language imposes a sole-causation requirement. That requirement cannot be squared with regulating disparate impacts, which almost always arise from diverse causes. Section 504 also focuses on the “individual” being treated differently, not on a group experiencing disparate effects.”); ECF 415 in *Payan v. Los Angeles Cmty. College Dist.*, No. 2:17-cv-01697 (C.D. Cal. Jan. 3, 2022) (requesting continued stay to provide opportunity to request Supreme Court review of whether private cause of action for disparate impact discrimination exists); *Doe v. BlueCross BlueShield of Tenn., Inc.*, 926 F.3d 235, 242 (6th Cir. 2019) (“Disparate-impact discrimination occurs when an entity acts for a nondiscriminatory reason but nevertheless disproportionately harms a protected group. ... But the Rehabilitation Act bars discrimination ‘solely by reason of her or his disability.’ ... That language does not encompass actions taken for nondiscriminatory reasons.”); cf. *Payan v. L.A. Cmty. Coll. Dist.*, Nos. 19-56111, 19-56146, 2021 U.S. App. LEXIS 25336, at \*9 (9th Cir. Aug. 24, 2021) (Lee, J., dissenting).

<sup>164</sup> 87 Fed. Reg. 47844.

<sup>165</sup> 87 Fed. Reg. 47830.

<sup>166</sup> 87 Fed. Reg. 47912, proposed definition of “Health program or activity.”

<sup>167</sup> 88 Fed. Reg. 63483.

<sup>168</sup> Maia Szalavitz, [The Pain Was Unbearable, So Why Did Doctors Turn Her Away?](#), WIRED (Aug. 11, 2021).

<sup>169</sup> 87 Fed. Reg. 47918, see § 92.210 for example. We note, however, that we would welcome an approach in the final Section 1557 rule that prohibits disability bias more generally across automated decision-making tools and systems.

<sup>170</sup> 88 Fed. Reg. 63483.