



November 13, 2023

**SUBMITTED ELECTRONICALLY**

The Honorable Xavier Becerra  
Secretary  
U.S. Department of Health and Human Services  
Attn: RIN: 0945-AA15  
200 Independence Avenue, SW  
Washington, DC 20201

**Re: Joint ITEM/CPR Coalition Comments on Proposed Rule Updating Section 504 Regulations: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities (RIN: 0945-AA15)**

Dear Secretary Becerra:

The undersigned members of the Independence Through Enhancement of Medicare and Medicaid (“ITEM”) Coalition and the Coalition to Preserve Rehabilitation (“CPR”) appreciate the opportunity to provide comments to the U.S. Department of Health and Human Services (“HHS”) in response to the landmark proposed rule that would update and advance protections for people with disabilities pursuant to Section 504 of the Rehabilitation Act of 1973 (“Proposed Rule”).<sup>1</sup> Section 504 is a cornerstone of civil rights legislation that prohibits discrimination on the basis of disability in programs and activities that receive Federal financial assistance, as well as in programs and activities conducted by any Federal agency.<sup>2</sup> Accordingly, the Proposed Rule applies to all recipients of HHS funding and financial assistance (“recipients”).

The ITEM Coalition is a national consumer- and clinician-led coalition advocating for access to and coverage of assistive devices, technologies, and related services for persons with injuries, illnesses, disabilities, and chronic conditions of all ages. Our members represent individuals with a wide range of disabling conditions, as well as the providers who serve them, including limb loss and limb difference, multiple sclerosis, spinal cord injury, brain injury, stroke,

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<sup>1</sup> *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*, 88 Fed. Reg. 63,392 (Sept. 14, 2023) (to be codified at 45 CFR 84), <https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities>.

<sup>2</sup> 29 U.S.C. 794

paralysis, cerebral palsy, spina bifida, hearing, speech, and visual impairments, myositis, and other life-altering conditions. CPR is a coalition of national consumer, clinician, and membership organizations that advocate for policies to ensure access to rehabilitative care so that individuals with injuries, illnesses, disabilities, and chronic conditions may regain and/or maintain their maximum level of health and independent function. CPR is comprised of organizations that represent patients – as well as the providers who serve them – who are frequently inappropriately denied access to rehabilitative care in a variety of settings.

The ITEM and CPR Coalitions submit this joint comment letter in strong support of the overarching goal of ensuring nondiscrimination in the provision of health programs and activities, and many of the undersigned members also plan to offer comments either individually or through other coalitions in response to the full scope of the Proposed Rule. We urge HHS to expeditiously finalize this rule to protect the ability of all individuals to access the health care services they need without fear or impact of discrimination.

The Proposed Rule represents a commendable effort on behalf of HHS to improve health equity by addressing equitable access to a number of benefits and services for people with disabilities. Specifically, HHS is proposing new regulations that would:

- Prohibit discrimination in medical treatment decisions;
- Prohibit the discriminatory use of value assessments;
- Clarify accessibility standards for web, mobile application, and kiosk accessibility; and
- Establish enforceable standards for accessible medical diagnostic equipment.

The Proposed Rule would also update the definition of “disability” and outdated terminology identifying people with disabilities to ensure consistency with statutory amendments to the Rehabilitation Act, enactment of the Americans with Disabilities Act (“ADA”) and the Americans with Disabilities Act Amendments Act of 2008 (“ADAAA”), and the Affordable Care Act (“ACA”).

## **I. Prohibition of Discrimination in Medical Treatment Decisions**

The Proposed Rule would implement new requirements prohibiting medical practitioners from discriminating against people with disabilities in medical treatment decisions. HHS provides extensive evidence of pervasive discrimination in treatment decisions particularly in organ transplantation, life-sustaining treatment, crisis standards of care, and participation in clinical research. Given the impact of the COVID-19 pandemic on people with disabilities, and the pervasive examples of discriminatory treatment decisions, denial of access to care, and decision-making criteria that served to devalue the lives of people with disabilities, the proposed rule states that these new provisions are essential protections against disability-based discrimination.

Ensuring that people with disabilities are appropriately treated by medical providers is a longstanding priority for both the ITEM and CPR Coalitions. In addition to the examples of discrimination provided in the preamble, we believe that the Final Rule would benefit from examples of best practices to mitigate the risk of discriminatory judgments. During the COVID-19 pandemic, the HHS Office of Civil Rights approved complaint settlements sought by

disability advocates 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 for physicians 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 to consider patient appeals of medical treatment decisions and public reporting 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 more difficult to detect and can be hidden behind professional judgment. This reality makes the Proposed Rule, and its prohibition of discriminatory treatment decisions, critical to ensuring equal access to medical care for people with disabilities.

It is important to note that the Proposed Rule and its construction do not intend to intrude on, or otherwise constrain, the exercise of professional medical judgment by providers.<sup>6</sup> The language 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 providers.<sup>7</sup> Given the subtle nature of this bias, and its persistence over time, we believe it is time for HHS to clearly prohibit discriminatory treatment decisions like those described within the Proposed Rule.

Denying any medical treatment on the basis of disability if the treatment would be provided to a similarly-situated patient without a disability constitutes discrimination on the basis of disability. The ITEM and CPR Coalitions believe it is paramount for treatment professionals to be better educated to better understand how to recognize their biases so they do not make erroneous assumptions about the values of patients with disability, thereby limiting their health care options and compromising care. This Proposed Rule makes significant strides toward achieving this goal and the ITEM and CPR Coalitions support and appreciate HHS's focus in this particular area.

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<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).

## **II. Prohibition of the Discriminatory Use of Value Assessments**

The Proposed Rule would also address discrimination on the basis of disability in the use of value assessment methods, which have been used by certain entities to determine whether certain treatments for people living with disabilities would be covered. When the health and lives of people with disabilities are devalued by society, as well as by the medical profession, such rules are necessary to protect individuals' equal access to care. The Proposed Rule marks 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 people with disabilities.

Quality Adjusted Life Years ("QALYs") and the similarly flawed Equal Value of Life-Years Gained ("evLYG") are value assessment mechanisms that, according to a 2019 report from the National Council on Disability, discriminate against people with disabilities by placing a lower value on the lives of individuals with disabilities and insufficiently accounting for outcomes they value.<sup>8</sup> The use of these measures in utilization management tools restricts patient access, thereby limiting the ability of patients and their providers to make decisions about the best treatment path. Unfortunately, the use of these measures places the most vulnerable patients, especially people with disabilities and other chronic conditions, at increased risk of adverse health outcomes and increases out-of-pocket costs associated with their care.

The ITEM and CPR Coalitions fully support the proposal to prohibit value assessment methods that place a lower value on life extension for a group of individuals based on disability bias, and where such methods are then used 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 an aid, benefit, or service.

## **III. Clarification Regarding Web, Mobile Application, and Kiosk Accessibility**

Like many industries, the health care sector is facing an increasing reliance on information and communication technology ("ICT") to serve patients, including people with disabilities. The patient experience in health care settings now involves the use of a wide range of ICT, such as electronic forms, check-in and billing kiosks, patient portals, and other tools that are frequently inaccessible to individuals with a wide range of disabilities. In addition, the COVID-19 pandemic led to a dramatic increase in the use of telehealth services, as well as other remote patient monitoring systems that may require input or operation by the patient in their home.

Historically, one of the major drivers of this inaccessibility was the lack of clarity as to what accessibility actually entails, which is why the ITEM and CPR Coalitions support and are grateful for the clarification provided in this Proposed Rule on specific technical standards for accessibility.

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<sup>8</sup> National Council on Disability, *Quality-adjusted Life Years and the Devaluation of Life with Disability* (Nov. 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).

The inaccessibility of ICT used in the health care setting provides as much of a barrier to equal access to health care services as does a doctor’s office without a wheelchair ramp, an exam table that cannot accommodate individuals with mobility impairments, or providing medical information without access to American Sign Language or braille. When a blind individual is handed an electronic tablet to check in for their appointment, detail any symptoms, or submit billing information, for example, they are prevented from equally benefiting from health care services unless effective accommodations are provided.

The ITEM and CPR Coalitions are proud of HHS’ commitment in this Proposed Rule to require covered entities to comply with specific standards for ICT accessibility, which will certainly help ensure that individuals do not face such discriminatory barriers. We are grateful that this Proposed Rule provides a solid starting point for regulating digital accessibility, but we believe that 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’ vendors and third-party partners into compliance as well.**

#### *Proposed Technical Standards*

HHS is proposing to add new accessibility requirements for web, mobile, and kiosk accessibility that establish clear technical standards with which all recipients are required to comply. HHS is proposing to adopt the Website Content Accessibility Guidelines (“WCAG”) 2.1 Level AA, which the World Wide Web Consortium developed to provide standards for web content access.

WCAG 2.2, Level AA, is the most recent standard that was published on October 5, 2023. As HHS notes, there are certain changes between WCAG 2.1 and 2.2; however, they are limited. The changes would eliminate one success criterion and add six Level A and AA criteria, including setting a minimum target size. 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 HHS 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 encourage HHS to update the rule regularly as new standards emerge.**

#### *Staggered Timeline for Compliance*

Larger recipients, defined as organizations with fifteen or more employees, would have two years following this proposal’s finalization to meet Level AA success criteria requirements

specified in WCAG 2.1. Small recipients, defined as organizations with less than fifteen employees, would have three years to meet these requirements. The Proposed Rule also applies to social media content that recipients offer the public to the extent that accessible features are available on a given social media platform.

We believe that staggering compliance dates based on the size of the recipient organization is largely arbitrary. The size of an organization is not a reliable measure of its ability to incorporate accessibility standards. The proposed compliance timeline is also exceptionally long, considering the rapidity with which websites and mobile apps are updated and how frequently web content is created. For years, recipients of federal funding have been on notice that their websites and mobile apps must be accessible under the ADA. Therefore, the Proposed Rule should not come as a surprise to these recipients.

Furthermore, WCAG 2.1 Level AA was designed to be achievable without regard to the size of a recipient's total population. Recipients do not need *years* to come into compliance with the proposed technical standards. To the extent recipients need some lead time to transition into full compliance with this standard, the transition time should be much shorter. We note that accessibility tools and services exist that can assist recipients in complying with the proposed standards in a faster timeframe. Therefore, HHS should not delay the required implementation of WCAG 2.1 Level AA based on the size of the recipient organization. Individuals with disabilities should not be forced to wait *years* to access important documents, services, activities, and programs that impact their health, function, and independence.

#### *Exceptions to Accessibility Requirements*

Certain compliance exceptions are allowed under the Proposed Rule for extenuating circumstances and previously uploaded content. For example, if it is determined that compliance would constitute an undue financial and administrative burden for the recipient, they may take other actions to increase accessibility and would need to ensure, to the maximum extent possible, that individuals with disabilities receive the benefits or services provided by the recipient. Additionally, the proposed technical standards would not be required for the following situations:

1. Archived web content;
2. Preexisting electronic documents— unless such documents are currently used by members of the public to apply for, gain access to, or participate in a recipient's programs or activities;
3. Web content posted by a third party;
4. Linked third-party content;
5. Individualized, password-protected documents; and
6. Course content for schools.<sup>9</sup>

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<sup>9</sup> The Department of Justice is proposing similar exceptions for its proposed rule. *See* 88 Fed. Reg. at 51,966-77.

Each of the exceptions are accompanied by limitations. If a limitation applies, the public entity must comply with the WCAG 2.1 Level AA accessibility standards. Our comments are limited to exceptions 2, 3, 4, and 5 and are detailed below.

***Exception #2: Preexisting Electronic Documents*** – “Conventional electronic documents” are defined as “web content or content in mobile apps that is in the following electronic file formats: portable document formats (PDFs), word processor file formats, presentation file formats, spreadsheet file formats, and database file formats.” If such documents—created either by or for a public entity’s use—are already available on the public entity’s app or website before this rule takes effect, they do not have to comply with the Proposed Rule’s requirements for accessibility.

This exception enshrines the status quo by allowing existing inaccessible documents to remain that way indefinitely. It is critically important that individuals with disabilities have access to preexisting conventional electronic documents. In the healthcare context, such preexisting documents can be instrumental in accessing care in the future. Directives on healthcare payment, coding, or coverage can govern medical decision-making long after they are published. Disputes related to coverage of healthcare claims can take years to resolve, making existing documents relevant for many years after application of this accessibility standard. Communications from a State to its Medicaid program or managed care organizations often come in the form of PDF manuals, letters, and guides that are not frequently updated. Additionally, even if they are updated, new documents do not always clearly “replace” the old documents. Partial revisions or modifications to existing documents make it necessary to have both versions accessible for comparison. Because of the importance and continued relevance of such documents, our coalitions support the elimination of this exception.

***Exception #3: Web Content Posted by a Third-Party*** – This exception focuses on web content that a third-party posts and is available on a public entity’s website. It only applies when the third party, rather than the public entity, posts content. This is true even when the public entity posts content that was originally created by a third-party such as scheduling tools, maps, calendars, or payment systems.

In the age of social media, where State and local government entities make frequent use of Facebook, X (formerly known as Twitter), or Instagram pages, third-party replies interacting with the content that the entity posts can be as important as the original post itself. Third-party comments can clarify remaining questions or can provide more up to date information than the original post. Additionally, such third-party comments can be an important way to voice grievances and gauge public opinion. For instance, third-party posts may include health information regarding where vaccines are available, opinions on certain healthcare treatments, and testimonials related to a particular healthcare provider. When such content is exempted from accessibility requirements, it limits the ability of those with disabilities to contribute to virtual public forums and glean important health information from them. As social media becomes an increasingly important part of the world, accessibility of such third-party information is necessary to fully participate in community life. Therefore, we support the elimination of this exception.

***Exception #4: Linked Third-Party Content*** – Under this exception, a recipient is not responsible for the accessibility of third-party web content linked from the public entity’s website. If the third-party website functions to allow the public to participate in or benefit from the recipient’s services (such as a third-party payment page), then the third-party website must comply with the accessibility standards. This exception does not apply to mobile apps that a third party operates.

Recipients heavily utilize third-party links to disseminate important information. For example, the COVID-19 pandemic has highlighted the need for up-to-date information on disease outbreaks and interventions to prevent community spread. Information such as where one can receive a vaccination, what doctors are accepting new patients, and where one can find community-based services and supports often require links to third parties who provide these services.

All third-party linked content should be required to comply with the proposed accessibility standards. If an individual with a disability cannot timely access third-party information, it may be too late for that person to receive time-sensitive health care services and support. Therefore, HHS should eliminate this exception.

***Exception #5: Individualized, Password-Protected Documents*** – This exception is for web-based conventional electronic documents that are about a specific individual, their property, or their account; and are password-protected or otherwise secured. For privacy and security purposes, important documentation containing health information, such as medical bills or explanations of benefits, are password-protected. This exception would significantly limit the ability of individuals with disabilities to timely access information related to their medical care. If such documents are not easily accessible, patients must go through a timely process to individually request that these documents be made accessible to them. There is no reason why individuals with disabilities should be forced to wait to access documentation that is critical to their healthcare. Therefore, our coalitions support the elimination of this exception.

#### **IV. Standards for Accessible Medical Diagnostic Equipment**

People with disabilities experience barriers to accessing medical care due to inaccessible medical diagnostic equipment (“MDE”). The Proposed Rule would establish standards for accessible MDE to help ensure that vital health care programs and activities are equally available to individuals with disabilities. More specifically, the Proposed Rule would establish standards and requirements for MDE, the purchasing or acquiring of new MDE, adapting existing MDE, and requirements for medical staff. The Proposed Rule adopts the U.S. Access Board’s Standards for Accessible MDE (“MDE Standards”) published in 2017 and sets general accessibility requirements for programs and activities that recipients provide through or with the use of MDE. In other words, a recipient cannot deny services that it would otherwise provide to a patient with a disability because the recipient lacks accessible MDE. This concept is consistent with federal disability non-discrimination laws that have been in effect for decades.

Accessibility of medical equipment has been a longstanding priority of the ITEM and CPR Coalitions, and we thank the HHS Office of Civil Rights (“OCR”) for including this issue in the Proposed Rule and offering critical enforcement of these accessibility standards. In previous



communications with the Department, the ITEM Coalition and other stakeholders, including the National Council on Disability, have noted that millions of Americans with disabilities encounter serious barriers to accessing medical care when equipment, especially diagnostic equipment, is not accessible to them. In particular, items such as examination tables and chairs, weight scales, mammography machines, MRI machines, and imaging equipment, are often unusable by people with certain disabilities. Oftentimes, patients with disabilities are refused treatment or are unable to undergo necessary parts of their examination due to inaccessibility and the failure to provide reasonable accommodations, such as a safe transfer or the concurrent use of a ventilator, to ensure these patients can access the care they need.

This can result in undiagnosed and untreated conditions, not to mention inconvenience, burden, and humiliation when people cannot receive care in a provider's office or other health care setting. Further, the increased use of at-home diagnostic tools, such as blood pressure monitors, thermometers, pulse oximeters, glucose monitors, and others has underscored the need for such equipment to be accessible to and usable by people with disabilities. As one example, blind individuals or persons with learning disabilities cannot be expected to read the solely visible output of such devices during a telehealth visit.

The ITEM and CPR Coalitions are pleased that HHS is finally proposing to adopt the U.S. Access Board's Standards for Accessible MDE. Adopting these long over-due standards into regulation by an enforcement authority such as the OCR will have a much more significant impact on providers and patients than the MDE standards have had in the past. Individuals frequently continue to encounter inaccessible MDE when they seek medical care. Accessible medical equipment is available and reasonable accommodations can be made in instances where providing accessible equipment would present an undue burden. However, the proliferation of inaccessible equipment persists, resulting in a clear discriminatory impact on individuals with disabilities.

The adoption of these already developed standards is a key first step to ensuring that recipients do not discriminate in the provision of their health programs and activities with regards to medical equipment. Making these standards enforceable would meaningfully decrease barriers to access for individuals with mobility, balance, strength, and respiratory impairments. However, to truly ensure nondiscrimination, equipment must be made accessible across the disability population. We urge HHS to consider additional medical equipment accessibility standards to account for the needs of individuals with visual, sensory, and other functional limitations. Finally, we note that the Access Board standards are limited (by legislative design) to a relatively narrow category of diagnostic equipment used primarily in physician's offices or hospitals.

We urge HHS to ensure that the Section 504 regulations consider the full range of medical equipment that must be made accessible, including at-home diagnostic tools, telehealth equipment, and other equipment frequently used in the health care setting. The development of such additional standards should not delay the adoption of the existing Access Board standards, which have been widely available for years and now must be made enforceable to ensure meaningful access to health programs and activities covered under Section 504.

## Requirements for Accessible MDE

The ITEM and CPR Coalitions support HHS' proposal requiring that physician offices, clinics, emergency rooms, hospitals, outpatient facilities, multi-use facilities, and other medical programs that do not specialize in conditions that affect mobility must ensure that at least 10% of MDE, but no fewer than one unit of each type of equipment, are compliant with the MDE Standards. Newly purchased, leased, or otherwise acquired MDE after the effective date of this rule must be accessible until this requirement is satisfied. Additionally, the Proposed Rule includes a dispersion requirement. It states that 10% of MDE meeting the standards must be dispersed proportionally across the entity. The proposed rule also addresses facilities that specialize in treating persons with conditions that affect mobility and requires that at least 20% of each type of MDE used, but no fewer than one unit of each type of MDE, must be in place to comply with MDE Standards. While we would prefer these requirements to be 100%, we note this dispersion requirement constitutes a low bar for compliance and believe it is more than reasonable to avoid undue burden.

### **V. Enforcement of Section 504**

The ITEM and CPR Coalitions strongly support the assessment in 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. We believe 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, and treatment standards, they do not necessarily have expertise in the civil rights that accrue to enrolled and eligible beneficiaries.

**The full spectrum 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 and to encourage them to refresh or maintain such basic operations as disability non-discrimination training for employees.**

While we recognize that enforcement with section 504 is complaint driven, we are also aware that expecting marginalized people to file formal complaints about the discrimination they are experiencing during the most difficult moments of their lives is an onerous requirement. This assumes that people have the motivation, information, and even access to file a complaint. This is even more salient for people with disabilities who have other marginalized identities. The Department of Justice recognized that relying on complaints alone to enforce civil rights protections was not adequate when it launched Project Civic Access,<sup>10</sup> which was a wide-ranging effort to ensure that counties, cities, towns, and villages comply with the ADA by eliminating

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<sup>10</sup> <https://archive.ada.gov/civicac.htm>

physical and communication barriers that prevent people with disabilities from participating fully in community life.

With a goal to facilitate enforcement of the ADA, and in many situations under section 504, Project Civil Access 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, we believe that an effort similar to Project Civil Access must be developed, funded, adequately staffed, and fully implemented.**

The ITEM and CPR Coalitions also wish to note that appropriate enforcement of personal rights requires systematic, accurate, timely, and comprehensive collection, analysis, and public reporting of disability data, including functional disability data for demographic purposes, as recommended by the Consortium for Constituents with Disabilities (“CCD”).

## **VI. Proposed Update to Definition of “Disability”**

The ITEM and CPR Coalitions are fully supportive of HHS’ statement in the Proposed Rule that the definition of disability is to be construed broadly. This statement is similar to current ADA regulations and is consistent with the purpose of the ADAAA, which is to ensure a “broad scope of protection” under the ADA and Rehabilitation Act. The view that the ADAAA adopted—and this regulation now officially proposes to adopt—stems from the Supreme Court’s stated view of disability.<sup>11</sup>

In furtherance of its goal to ensuring the broadest coverage allowable under Section 504, the Proposed Rule updates the definition of Disability. With respect to an individual, HHS construes disability to mean “(i) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (ii) a record of such an impairment; or (iii) being regarded as having such an impairment as described in paragraph (f) of this section.”<sup>12</sup> Mirroring current ADAAA regulations, the Proposed Rule’s definition of disability articulates three methods, or prongs, of determining whether an individual has a disability: (1) the “actual disability” prong; (2) the “record of” prong; or (3) the “regarded as” prong. The ITEM and CPR Coalitions are grateful that HHS is clarifying once more in this Proposed Rule that each of these prongs should be interpreted broadly and in favor of expansive coverage. Additionally, the Proposed Rule specifically adds Long COVID to the list of physical and mental impairments, which the ITEM and CPR Coalitions also fully support.

## **VII. Guidance on the Phrase “Solely by Reason of His or Her Disability”**

The fight for disability civil rights has long been plagued by the phrase, “solely by reason of his or her disability,” found in Section 504. The problem lies in that, to many, the phrase is commonly construed to mean that only intentional discrimination is prohibited, and that other forms of discrimination are not actionable under the law. For decades, the disability community

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<sup>11</sup> *School Board of Nassau County v. Arline*, 480 U.S. 273 (1987) (holding that the definition of disability under Section 504 is to be viewed expansively).

<sup>12</sup> 88 Fed. Reg. at 63,459.

has expended extraordinary resources fighting this false and ahistorical construction of Section 504.

HHS includes this phrase within Section 84.68(a) of the Proposed Rule, but provides no additional clarity defining the language. Specifically, the Proposed Rule states, “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.”<sup>13</sup> 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.”<sup>14</sup>

Because of this lack of clarity, 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 ITEM and CPR Coalitions suggest that the regulations could include text such as:

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

As used in this part, “solely on the basis of disability” is consistent with, and does not exclude, 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.

The ITEM and CPR Coalitions believe it is critical that HHS provides some additional regulatory language in the final rule, such as the suggestions listed above, that explicitly defines and clarifies the statutory phrase in favor of broad coverage, as Congress intended.

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We appreciate the opportunity to comment on this landmark Proposed Rule and further commend HHS’ continued efforts to enhance communication and prevent discrimination against individuals with disabilities in health care. A strong Final Rule would make significant strides toward achieving this goal. Should you have any further questions regarding this letter, please contact the ITEM and CPR Coalition Co-Coordinator at [Peter.Thomas@PowersLaw.com](mailto:Peter.Thomas@PowersLaw.com) or [Michael.Barnett@PowersLaw.com](mailto:Michael.Barnett@PowersLaw.com) or by calling 202-466-6550.

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<sup>13</sup> See 88:177 Fed. Reg. at 63505

<sup>14</sup> See 88:177 Fed. Reg. at 63473

Sincerely,

**The Undersigned Members of the ITEM and CPR Coalitions**

Access Ready, Inc.  
ACCSES  
Alexander Graham Bell Association for the Deaf and Hard of Hearing  
All Wheels Up  
Allies for Independence  
American Academy of Physical Medicine and Rehabilitation  
American Association of People with Disabilities  
American Association on Health and Disability  
American Cochlear Implant Alliance  
American Congress of Rehabilitation Medicine  
American Council for the Blind  
American Macular Degeneration Foundation  
American Medical Rehabilitation Providers Association  
American Music Therapy Association  
American Occupational Therapy Association  
American Spinal Injury Association  
American Therapeutic Recreation Association  
***Amputee Coalition\****  
Association of Academic Physiatrists  
Association of People Supporting Employment First (APSE)  
Association of Rehabilitation Nurses  
Association of University Centers on Disabilities  
Autistic Women & Nonbinary Network  
Blind Veterans Association  
Blinded Veterans Association  
***Brain Injury Association of America\****  
***Center for Medicare Advocacy\****  
***Christopher and Dana Reeve Foundation\****  
Council of State Administrators of Vocational Rehabilitation (CSAVR)  
Easterseals, Inc.  
Easterseals DC MD VA  
***Falling Forward Foundation\****  
Institute for Matching Person and Technology  
International Eye Foundation  
Lakeshore Foundation  
Long Island Center for Independent Living, Inc.  
Medicare Rights Center  
Muscular Dystrophy Association  
National Association for the Advancement of Orthotics and Prosthetics  
National Association of Rehabilitation Research and Training  
National Association of Social Workers (NASW)  
National Disability Rights Network (NDRN)

National Registry of Rehabilitation Technology Suppliers  
Prevent Blindness  
Prevention of Blindness Society of Metropolitan Washington  
RESNA

*Spina Bifida Association\**

*The ALS Association\**

The Simon Foundation for Continence

The Viscardi Center

Uniform Data System-Med Rehab

United Cerebral Palsy

*United Spinal Association\**

VisionServe Alliance

*Indicates ITEM and CPR Coalition Steering Committee Member\**