

# Summary of HHS Section 504 Proposed Rule

## Summary

For far too long, people with disabilities have experienced discrimination when accessing healthcare, interacting with welfare systems, and when trying to access other human services.

**We have an exciting opportunity right now to transform access to these services! We need your help, to ensure the rule reflects the true diversity and needs of the community.**

The Department of Health and Human Services (HHS) recently shared a proposal to expand and update Section 504 of the Rehabilitation Act, a law that prevents discrimination based on disability by entities that receive federal funding. [We need the community's help!](#)

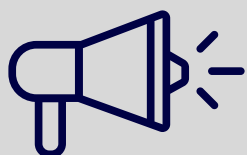
**If you have experienced medical discrimination or discrimination in any other healthcare or human service setting, HHS needs to hear your story. [Please share your story of why you need this rule and how you've been affected by the issues it addresses. Stories are due by 11:59 pm on Sunday, November 12, 2023.](#)**

Once finalized and enacted, the proposed rule, "[Discrimination on the Basis of Disability in Health and Human Services Programs and Activities](#)," will mark an incredible advancement in disability civil rights.

The proposed rule expands the protections of Section 504 in many ways, including:

- Ensures that access to quality medical care, including treatment options and organ transplants, cannot be compromised by a doctor's biased opinion on a disabled patient's "quality of life;"
- Ends the use of discriminatory value-assessment methods in medical treatment;
- Reduces barriers for disabled parents, such as ensuring that their children cannot be taken away on the basis of the parent's disability;
- Creates new standards for web, mobile, and kiosk accessibility;
- Adopts clear requirements for accessible medical equipment;
- ...and more!

The proposed rule will also update the outdated and harmful language to refer to disability in some past laws and policies. HHS has proposed that the language be updated to better reflect modern legal, social, and legislative norms.



As AAPD President and CEO Maria Town [said at the press conference announcing the rule](#) in September, [these new policies will be life-changing and life saving for disabled people.](#)

**[CLICK HERE to share your story with AAPD NOW!](#)**

All stories or reasons for supporting this rule are helpful. The deadline to submit your story to AAPD is 11:59 PM on November 12, 2023.

## Sharing Your Story

As AAPD President and CEO Maria Town shared when this rule was announced,

“I was born disabled. Some of my earliest memories are in doctor’s offices and clinics for therapies and treatments. And like so many disabled people, my initial experience of and understanding of my own body, my health, and my disability status was defined by medical professionals within the US healthcare system.

Their assessments and perspectives on my competency and the value of my life impacted the quality of care and treatments that I received. These clinician’s judgments significantly informed the expectations that others had of me, that then shaped my education, my employment, my ability to live in the community, and my ability to form a family.”

When clinicians or other health and human service providers have negative biases or assumptions about a disabled person, it can have far-reaching and disastrous consequences for their health and their families.

**No matter what your experience with disability discrimination is, if you feel affected by any of the topics related to the rule, we want to hear from you.**

## Resources For Sharing Your Story

- For more information on the proposed changes, read the attached fact sheet below.
- [Read or watch Maria Town’s speech at the rule announcement here](#), which provides several examples of the important impact of this rule.
- Read [HHS’ fact sheet about the proposed rule here](#).
- Check out this [helpful resource from the Autistic Self Advocacy Network](#). It is called “Sharing Your Story for Political Purposes” and includes Plain Language and Easy Read versions.
- Some questions and prompts that might help you think through sharing your story are featured below.

## Some examples of experiences you could share about include:

- Having received worse quality medical treatment due to discriminatory biases or stereotypes about disability,
- Inability to access care because of inaccessible scales, being told no one can transfer you to an examination table, or asked to transfer to medical equipment in unsafe ways,
- The negative impacts of discriminatory crisis standards of care on yourself or in the care of a loved one during the ongoing COVID-19 pandemic,
- Denial or deprioritization for organ transplantation because of judgements doctors have made about your quality of life because of your disability,
- An agency threatened to or actually took away your parental rights because of your disability and ableist judgements they may have made about your ability to parent,
- Barriers when trying to access the services or information related to healthcare or child welfare providers on social media platforms and/or on mobile apps,
- Difficulties requesting accommodations and flagging issues with accessibility when using websites or mobile apps run by state or local entities, or problems with inaccessible medical records
- Inaccessible information on third party websites related to your health care or social services, such as patient portals, benefits portals, social media, links to other sites such as pharmacies, etc.

## Some additional questions you could ask yourself include:

- How would my medical care and my life be different if I knew negative assumptions about my disability would not play a role in my healthcare access?
- What barriers do I encounter most often when trying to access healthcare and other services?
  - What accommodations, supports, and services would change this experience?
- Is there preventative medicine or screenings that I should receive but cannot access because of inaccessible equipment or websites?
- What would my healthcare interactions look like if all of my access needs were proactively considered and met?

## New Provisions

### Medical Treatment

- Providers may not restrict or deny appropriate medical treatment to a disabled patient when the denial is based on:
  - Biases against a disabled person
  - Judgments that an individual will be a burden on others, due to their disability
  - A belief that the life of a person with a disability has lesser value than that of a non-disabled person
- Providers may not deny or limit appropriate medical treatment to a disabled patient if the same treatment would be offered to a person without a disability
- Providers must address disability discrimination in organ transplantation processes

### Value Assessment Methods

- Discriminatory value assessment methods – in which a lower value is placed on life-extension for people with disabilities – may not be used
- Value assessments may not restrict a patient's access to quality and timely care, services, aids, and/or benefits

### Child Welfare System

- Prohibits discrimination toward disabled people by child welfare program or activities
  - This includes decisions based on speculation, stereotypes, or generalizations about a parent, caregiver, foster parent, or prospective parent with a disability
  - This also prohibits discriminatory decisions about a child with a disability
- Requires child welfare agencies place qualified individuals with disabilities in the most integrated setting appropriate to the needs of the child
- Prohibits child welfare programs from petitioning for the removal of a child or termination of a parent's legal rights based solely on a parent's disability

### Web, Mobile, and Kiosk Accessibility

- Requires specific standards for accessible web content and mobile applications
  - Many of these standards match what was proposed by a recent new rule from the Department of Justice
- Adopts WCAG 2.1 as the technical standard for web and mobile app accessibility
- Requires kiosks be accessible
  - Allows providers to include a work-around procedure for inaccessible kiosks (e.g., having people go straight to the desk) as long as the patient is provided the same access, care, services, and confidentiality

## Accessible Medical Equipment

- Establishes requirements for accessible medical equipment for people with disabilities, including general accessibility requirements for programs and activities that use medical diagnostic equipment (MDE)
- Requires providers who use an examination table must have at least one accessible table and providers who use a scale to have at least one accessible scale. Accessible equipment must be obtained within two years of the rule's effective date.
- Proposes mandatory staff training to operate accessible MDE and properly assist patients with disabilities.

## Integration Mandate

- Updates standards of community integration for disabled people to align with the Olmstead decision, which states that people have the right to state-funded support and services in their communities rather than institutions
- Organizations who receive funds from HHS must serve people with disabilities in the most integrated setting possible, consistent with the Olmstead decision.

## Language and Definitions

- The second section of the rule revises previous Section 504 regulations to ensure that key language and definitions are updated in accordance with current legislation and court cases, for example, the Americans with Disabilities Act or the Affordable Care Act. The proposal includes adding updated definitions for many important terms.