Discrimination on the Basis of Disability
by Federally Funded Health Care Providers

Excerpts from Proposed Rule 0945-AA15 of the
U.S. Department of Health and Human Services

With Commentary on Health Care Services for
Adult Patients with Developmental Disabilities

by Thomas F. Coleman
September 12, 2023

Produced by Spectrum Institute for
the Alternatives to Guardianship Project

WARNING

Discriminate at Your Own Risk

The federal government is paying attention to the medical rights of adult patients with mental or developmental disabilities.

Providers should too.

A new HHS rule will place the burden of proof on providers to justify the refusal to allow adult patients with mental or developmental disabilities to make their own medical decisions or delegate such authority to others.

Under this rule, federal nondiscrimination law will recognize the right of adult patients to use medical supported decision-making.

Under this rule, providers have a duty to modify existing policies and practices to accommodate the decision-making rights of these patients, unless there is evidence that such accommodations are not required.

Unjustified denial of medical decision-making rights may result in a complaint to the HHS Office of Civil Rights.

Report Online:

https://alternativestoguardianship.com/hhs-rule-report.pdf

Contents

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This Report

Section 504 of the Rehabilitation Act of 1973 has been on the books for 50 years. It prohibits recipients of federal funds, whether public entities or private firms, from discriminating in the delivery of services on the basis of disability. Section 504 is a companion law to the Americans with Disabilities Act (ADA).

The U.S. Department of Health and Human Services enforces Section 504 with respect to health care providers. HHS estimates that approximately 92% of doctors, 43% of dentists, and all hospitals are subject to section 504. Rules to implement this law are adopted by the department. The HHS Office of Civil Rights (OCR) investigates discrimination complaints filed against health care providers.

HHS has just published a proposed new rule to enforce Section 504. It is soliciting comments on the rule from providers, patients, and the public. Once finalized, it will apply to most health care providers in the nation.

The proposed rule does not create new law. It does, however, provide greater clarity on the duties of providers not to discriminate as well as the rights of patients with disabilities to have equal access to health care services.

The proposed rule gives more detailed guidance regarding health care services to adults with mental or developmental disabilities. Since violations of the rule, when it takes effect, could result in discrimination complaints to OCR, it is in the self interest of health care providers to educate themselves about the rights of adult patients with mental or developmental disabilities and their duties to this patient population under Section 504.

This report is intended to educate these patients and their providers on such issues.

Highlights

✔ Patients with disabilities are often subject to discrimination.

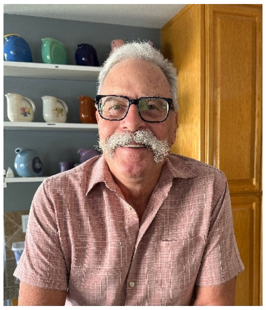
✔ A 2021 study found that many doctors have biased or stigmatized perceptions of people with disabilities.

✔ A 2022 study found that many doctors are unsure of their legal responsibilities to this patient population.

✔ The proposed rule advises providers on how to avoid discrimination against patients with mental or developmental disabilities.

✔ Editorial comments in this report give further insight into the duties of providers to offer ADA accommodations, ensure effective communication, respect patient rights, be flexible in obtaining consent, and allow patients to use supported decision-making arrangements.

The Author



Thomas F. Coleman has been practicing law since 1973. His civil rights advocacy has involved research, education, litigation, consulting, and media outreach. For the last decade, Coleman has concentrated his efforts on disability rights, the ADA, and guardianship reform. He has published many articles and made numerous presentations on issues such as legal capacity, medical self-determination, and supported decision-making.

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HHS Authority

The Department of Health and Human Services (HHS or the Department) is committed to protecting the civil rights of individuals with disabilities under section 504 of the Rehabilitation Act of 1973 (section 504). Section 504 has applied to medical care providers that receive Federal financial assistance from the Department for approximately fifty years.

The health care sector in the United States is quite broad, encompassing about 490,000 providers of ambulatory health care services and 3,044 hospitals. It includes 168,459 offices of physicians; 124,384 offices of dentists; 141,853 offices of other health care practitioners; 7,192 medical and diagnostic laboratories; 24,619 home health care service providers; and 19,625 outpatient care centers. Most of these entities receive Federal financial assistance.

The Department's Office for Civil Rights (OCR) enforces federal civil rights laws the Health Insurance Portability and Accountability Act (HIPAA) Privacy, Security, and Breach Notification Rules, and the Patient Safety Act and Rule. OCR investigates complaints for alleged violations of these laws to identify discrimination and to take action to correct problems. It conducts compliance reviews, requires corrective and remedial action, promulgates policy and regulations, and provides technical assistance and public education for the American people. OCR promotes the full engagement of individuals in decisions related to their health care.

The Department estimates that approximately 92% of doctors, 43% of dentists, and all hospitals receive federal financial assistance from the Department and are thus subject to section 504. The Department's section 504 rules apply to this universe of recipients.

Federal Nondiscrimination Laws

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs and activities that receive Federal financial assistance. OCR enforces section 504 as well as two other statutes that prohibit discrimination on the basis of disability. Title II of the Americans with Disabilities Act (ADA) and section 1557 (section 1557) of the Patient Protection and Affordable Care Act (ACA).

The proposed regulation attempts to balance state autonomy with the necessity to create a federal benchmark that will provide a uniform level of nondiscrimination protection across the country. It is recognized that the states generally have laws that relate to nondiscrimination against individuals on a variety of bases. Such State laws continue to be enforceable, unless they prevent application of the proposed rule. The proposed rule explicitly provides that it is not to be construed to supersede State or local laws that provide additional protections against discrimination on any basis articulated under the regulation. Provisions of State law relating to nondiscrimination that are "more stringent" than the proposed Federal regulatory requirements or implementation specifications will continue to be enforceable.

HHS Findings

- People with disabilities are often excluded from health programs and activities and denied an equal opportunity to participate in and benefit from quality health care. That discrimination contributes to significant health disparities and poorer health outcomes than persons with disabilities would experience absent the discrimination.

- Only 40.7 % of physicians surveyed were confident of their ability to provide the same quality of care to patients with disabilities.

- Medical literature, government agency reports, and court decisions demonstrate that individuals with disabilities face discrimination at every stage of the medical treatment process.

- Biases and stereotypes about the impact of disability affect decisions in different contexts, including diagnoses, day-to-day treatment decisions, emergency care decisions, and the allocation of scarce medical resources in health crises.

- Although section 504 has prohibited discrimination in any program or activity receiving Federal financial assistance since it was enacted, discrimination continues to underpin health inequities faced by people with disabilities. People with disabilities have reduced access to medical treatment, a reality that leads to significant health disparities and poorer health outcomes.

- A 2021 study found that large proportions of practicing U.S. physicians appeared to hold biased or stigmatized perceptions of people with disabilities.

- A related study released in January 2022 found that many physicians are uncertain about their legal responsibilities resulting from laws prohibiting discrimination on the basis of disability or how to provide equitable care to patients with disabilities.

- Another study published in October 2022 found that some providers seek ways to avoid treating patients with disabilities and to discharge them from their practice.

- Stereotypes about the value and quality of the lives of people with disabilities have led to discriminatory medical decisions.

The Proposed Rule

The Department proposes to amend its existing regulation implementing section 504 for federally assisted programs and activities to address the obligations of recipients of Federal financial assistance to comply with section 504 across a variety of contexts.

The Department is issuing this proposed rule to address discrimination on the basis of disability by recipients of HHS financial assistance. The proposed regulation is intended to help health care providers and patients better understand their rights and responsibilities under section 504.

The Department is issuing this proposed regulation to offer clear and specific requirements to help recipients better understand their obligations under the law and to help individuals with disabilities better understand their rights. The Department believes this added clarity and transparency will support recipients in providing programs and activities free of discrimination on the basis of disability.

Medical Treatment

Through this proposed rule, HHS is adding provisions to enforce Section 504 addressing discrimination in medical treatment on the basis of disability. 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 or mental health condition, injury, disorder, or symptom, whether or not the condition constitutes a disability and whether the medical approach is preventive, curative, rehabilitative, or palliative. t includes the use of a wide range of regimens for both physical and mental conditions, interventions, or procedures, such as surgery; the prescribing, dispensing, or management of medications; exercise; physical therapy; rehabilitation services; and the provision of durable medical equipment.

Section 84.56(b)(1) of the proposed rule addresses denial of treatment. It makes explicit that a recipient is prohibited from denying or limiting medical treatment to a qualified individual with a disability when the denial is based on (I) bias or stereotypes about a patient's disability; (ii) judgments that an individual will be a burden on others due to their disability, including, but not limited to, caregivers, family, or society; or (iii) a belief that the life of a person with a disability has a lesser value than that of a person without a disability, or that life with a disability is not worth living.

Denying, limiting, or withholding treatment for any of the prohibited reasons is discrimination on the basis of disability because the decision is driven by the recipient's perception of disability rather than by consideration of effectiveness of the treatment or other legitimate reasons. However, the imposition of eligibility criteria that screen out people with disabilities from receiving the benefit of medical care is not discrimination when the criteria are shown to be necessary for the provision of this aid, benefit, or service. The rule does nothing to disturb the ability of physicians to exercise their professional judgment based on the current medical knowledge or the best available objective evidence on the issue at hand.

[*Editorial Comment*: Denying an adult patient the right to make a medical decision or to delegate decision-making to another person of their choice would be a form of disability discrimination unless the denial is based on an assessment of incapacity performed with scientifically valid standards by a professional who is qualified to make such a forensic assessment. The rule explains that denial of treatment must be a reasonable determination "based on current medical knowledge or the best available objective evidence" and not "based on bias or stereotypes about a patient's disability."]

The proposed rule is designed, in part, to address discriminatory conduct based on the belief that persons with intellectual, mental health, and developmental disabilities are entitled to less bodily autonomy than nondisabled persons.

Consent

The proposed rule addresses the issue of consent. Section 84.56(c)(2)(I) makes clear that this section does not require a recipient to provide medical treatment to an individual where the individual, or the person legally authorized to make medical decisions on behalf of that individual, does not consent to that treatment.

Denial of treatment is not the only way a recipient can discriminate on the basis of disability in its covered programs or activities. The operations of covered health care providers are not typically limited to providing treatments. They also include the provision of advice and <u>the process of providing information</u> to comply with informed-consent requirements established by state law and otherwise.

Proposed paragraph (c)(2)(ii) makes clear that <u>discrimination in obtaining informed consent is prohibited</u> independently of whether that discrimination is followed by a decision to withhold treatment — or whether such a subsequent decision to withhold treatment is itself discriminatory.

Providing Information

Section 84.56(c)(3) of the proposed rule addresses the information exchange between the recipient and the patient with a disability concerning the provision of information and potential courses of treatment and their implications. Under the proposed rule, a provider is prohibited from discriminating on the basis of disability in seeking consent for the decision to treat or to forego treatment.

[*Editorial Comment*: Since the rule prohibits discrimination in the exchange of information related to consent for treatment, a provider must give a patient with a developmental disability complete and accurate information regarding their right to make medical decisions independently, with assistance from another person, or to delegate decision-making authority to a person of their choice. Simply advising the patient or parent to get a guardianship would be a form of discrimination unless a competent capacity evaluation has been performed by a professional qualified to make such a forensic assessment. Without such an evaluation, advice to get a guardianship would be based on biases or stereotypes rather than medically competent information.]

Supported Decision-Making

Over the past decades, in keeping with these U.S. Supreme Court decisions, federal courts and federal agencies have regularly acknowledged an affirmative obligation under section 504 to ensure that recipients [e.g. health care providers] provide individuals [e.g. patients] with disabilities reasonable modifications to policies and practices to ensure effective communication and meaningful access to programs and activities of the recipient.

Reasonable modifications 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. Supported decision-making is an approach used to assist individuals with disabilities in making decisions in an informed and accessible way, through the provision of person-centered decision-making that focuses on the wants and needs of the individual receiving support.

Supported decision-making allows an individual with a disability to collaborate with trusted sources and make their own decisions without the need for a substitute decision-maker. Supported decision-making reinforces an individual's autonomy in decision-making, involves the individual in the decision-making process, and recognizes that in some instances assistance may be needed.480 It is the role of the supporter to help the individual with a disability understand the range of options and the implications of each, leaving the ultimate decision to the individual with a disability

As defined in the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act,481 supported decision-making means assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions, including health-related decisions, which enables the individual to make the decisions, and in communicating a decision once made, consistent with the individual's wishes. NCD [National Council on Disability] has recognized the potential autonomy benefits of supported decision-making. In health care, supported decision-making may mean supports and services from friends, family members, and professionals that help an adult with a disability make their own decisions, including assistance monitoring health; obtaining, scheduling, and coordinating service; understanding information and options; making decisions; and communicating those decisions to others.

The supporter's role may include helping an individual to understand the range of possible treatment options and their implications, placing that information in terms they can understand, and helping the individual apply their own values to the decision. In research contexts, supported decision-making may include a supporter providing such assistance in the informed consent process.

As an example of a reasonable modification in supported decision-making, a health care provider may need to modify their policy on disclosing information to third parties about a medical procedure, if the individual with a disability needs their supporter to help understand their treatment options. A human service provider who normally does not share benefit applicant information with third parties may need to make additional copies of information about an individual with a disability's benefits eligibility to share with their supporter so the supporter can help explain the options available

In the context of human services, supported decision-making may be used to assist an individual with a disability who requires decision-making support to make decisions regarding different options, choose whether or not to continue a particular course of service-provision, and otherwise express their will and preference with the assistance of a supporter to ensure that the individual fully understands the range of options available and the implications of each. Once the individual has made a decision, the supporter can help to translate, explain, or substantiate that position to medical professionals, human services systems, or other relevant entities. In some instances, however, the use of supported decision-making will not require any modification at all. For example, a person with a disability may decide to obtain support for a decision by consulting with others ahead of time, but be in a position to communicate a decision to a provider without any reasonable modifications.

Communications

Communication failures in the context of the receipt of health and human services can be life-altering or even life-ending.564 Ensuring that communications with individuals with disabilities are as effective as communications with others (commonly referred to as "effective communication") helps to avoid such communication failures and protect the health of individuals with disabilities. Over the years, OCR has received numerous complaints alleging that recipients have failed to ensure effective communication to individuals with disabilities or failed to provide appropriate auxiliary aids and services to individuals with disabilities in both the health care and social services context.565 In many of these cases, OCR identified compliance concerns with Federal nondiscrimination laws and entered into agreements with recipients to address these concerns.

Notwithstanding OCR's extensive enforcement activities in this area, including through complaint resolutions, compliance reviews, and the provision of technical assistance, ineffective communication with individuals with disabilities remains a persistent and significant discrimination issue.

Part of effective communication is ensuring that individuals with disabilities, including those with cognitive, neurological, and psychiatric disabilities, have the appropriate information necessary to make health care decisions. Communication between a person seeking medical treatment and their health care provider is a basic component of health care and in some circumstances leads to a formal process of granting of permission for treatment, usually referred to as informed consent. The success of this process requires the person seeking treatment to understand the options and make an informed choice in determining the course of treatment.

Research suggests that methods of communication, along with the quality of the interactions between the provider and the patient with a cognitive disability, play more important roles in the patient's ability to make informed decisions than intellectual and adaptive functioning.

The Department is concerned that some providers erroneously believe that certain patients with disabilities, especially those with cognitive, neurological, or psychiatric disabilities, are unable to understand discussions concerning their health care, and instead of communicating directly with the patient, communicate only with family members or companions. In instances where providers base these communication decisions on stereotypes or misconceptions about the patient's ability to understand or make medical decisions, they deny the patient autonomy and control over their health care. Fundamental concepts of federal disability rights laws, including rights to effective communication and reasonable modifications, require that individuals with disabilities, including those with cognitive, neurological, and psychiatric disabilities are afforded the information needed to have an equal opportunity to make informed health care decisions.

Effective communication for patients with cognitive, neurological, and psychiatric disabilities may require auxiliary aids and services or strategies different from those employed with patients with other disabilities. For example, while an individual who is deaf or hard of hearing may require an ASL interpreter to effectively communicate with a provider, an individual with a cognitive disability may require additional time with the provider to ask questions and receive plain language answers about a specific health care decision.

A specific type of auxiliary aid or service may be the acquisition or modification of equipment or devices, including for augmentative and alternative communication, and the provision of training and assistance to the individual with a disability on how to use them. Augmentative and alternative communications devices include, but are not limited to, speech generating devices, single-message devices, computers, tablets, smartphones, amplification devices, telecommunications devices, voice amplifiers, artificial phonation devices, picture and symbol boards, paper-based aids, and other equipment or devices used to compensate for impairments to speech-language production or comprehension, including spoken and written modes of communication.

In some instances, the use of augmentative and alternative communication is necessary for individuals with certain disabilities that impair speech production and comprehension to access vital health and human services programs and activities. Often, the most effective way for recipients to ensure effective communication is to provide training on the use of this equipment.

Section 504 also requires recipients to provide reasonable modifications to policies, practices, or procedures to individuals with disabilities when necessary to avoid discrimination unless the modification would fundamentally alter the nature of the program or activity at issue. Reasonable modifications may include modifications to how a provider communicates with or delivers information to a patient with a disability. For example, a reasonable modification for a patient with a mental disability may be to allow a third-party support person to join the conversation and allow that person to assist the patient in understanding their options and coming to an independent decision on how to proceed. The person with a disability may be in a supported decision-making arrangement with the third-party support person, but no such formal role is required.

Another reasonable modification may be for the recipient to provide information in a format that is accessible to individuals with cognitive, developmental, intellectual, or neurological disabilities such as through plain language. NCD has urged the Department to issue guidance to medical professionals requesting that they explain procedures and draft documents in plain language to better serve patients with disabilities.579 Under some circumstances, plain language may be a reasonable modification to remove barriers between individuals with certain disabilities and the information necessary to make informed health and human services decisions. Information written in plain language may afford individuals with certain disabilities an equal opportunity to comprehend important service, program, or activity information. Sometimes, a plain language oral explanation, instead of a written one, may be a sufficient modification. However, in many circumstances, it may be a fundamental alteration of the nature of a recipient's program or activity to require extensive technical documents to be produced in plain language.

Section 84.77(a)(1) of the proposed rule requires that a recipient [e.g. health care provider] take appropriate steps to ensure that communications with applicants, participants, members of the public, and companions with disabilities are as effective as communications with others in such programs or activities. Proposed § 84.77(a)(2), as well as the definition section at § 84.10, defines a companion as a family member, friend, or associate of an individual seeking access to a program or activity of a recipient, who, along with such individual, is an appropriate person with whom the recipient should communicate. The proposed text at § 84.77(b)(1) requires that a recipient provide appropriate auxiliary aids and services to individuals with disabilities, where necessary to afford such individuals an equal opportunity to access the benefit or service in question. Section 84.77(b)(2) states that the type of auxiliary aid or services needed will vary in accordance with various factors. That paragraph further provides that, in determining what types of auxiliary aids and services are necessary, a recipient shall give primary consideration to the request of the individual with a disability. In addition, it states that to be effective auxiliary aids and services must be provided in accessible formats, in a timely manner, and in such a way as to protect the privacy and independence of the individual with a disability.

The burden of proving that compliance with any section in this subpart would fundamentally alter the nature of a program or activity or would result in undue financial and administrative burdens rests with the recipient.

Reference Materials

Guidance for Patients, Families, Providers and Others on Medical Decision-Making (link)

A comprehensive guidebook on the medical decision-making rights of adult patients with developmental disabilities is now available. It has information for patients, families, health care providers, state agencies, and professional associations. The book includes an annotated bibliography of relevant state and federal statutes, regulations, and court cases.

Transitioning to Adulthood: Resources for Patients, Parents and Medical Providers (link)

This annotated bibliography directs readers to a variety to resources to help patients with developmental disabilities have an effective and meaningful relationship with doctors, clinics, and hospitals. While some materials are helpful to patients of any adult age, most of them are geared for teens who are preparing to assume primary responsibility for their medical care once they become adults. The bibliography has four sections: For Patients, For Parents, For Providers, and Research.

Medical Decision Making Options: A Summary of Legal and Medical References for Health Care Providers, Patients and Families (link)

This report explains that medical decision-making should not be an all (independent) or nothing (guardianship) proposition. Other options exist for medical professionals to receive informed consent for medical services and medications. Medical and disability stakeholders are invited to work together to identify ways to improve the medical decision-making evaluation process and to better protect the rights of these patients.

CALIFORNIA SCDD

State Council on Developmental Disabilities

NEWS RELEASE

FOR IMMEDIATE RELEASE
September 7, 2023

Contact: Office of Policy and Public Affairs
Policy@scdd.ca.gov

The U.S. Department of Health and Human Services (HHS) Proposed a New Rule Against Discriminating Against People with Disabilities in Healthcare and Human Services Programs

SACRAMENTO—Today, HHS, through its Office for Civil Rights (OCR), introduced a rule that works to stop discrimination based on a disability. This rule, called "Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance," updates important parts of current regulations that help people with disabilities get healthcare and human services under Section 504 of the Rehabilitation Act (Section 504), passed by Congress in 1973.

"It's 2023, yet for many Americans, accessing basic health needs is still challenging. Some persons with disabilities may have to drive hours to get an accessible mammogram or receive the benefits and advancements of our health care system. This historic proposed rule will advance justice for people with disabilities and help ensure they are not subjected to discrimination under any program or activity receiving funding from HHS just because they have a disability," said Secretary Xavier Becerra.

"While we have made significant progress since Section 504 was signed into law nearly 50 years ago, there is more work for us all to live up to its promise to the American people," said HHS Office for Civil Rights (OCR) Director Melanie Fontes Rainer. "Today's rule is long overdue and a major step forward in the fight to ensure that people with disabilities are not excluded from or discriminated against in health care and social services across the United States. Once again, the Biden-Harris Administration is making clear that we must do better and stand up to improve equitable access to health care, free of discrimination."

"The COVID-19 pandemic shone a spotlight on the discrimination that too many people with disabilities continue to face, from denial of medical treatment due to ableism, to inaccessible medical equipment and websites, to having no choice but to receive services in institutional settings," said Alison Barkoff, who leads the Administration for Community Living. "ACL is pleased to have collaborated with the Office for Civil Rights to ensure the rule addresses the most pressing issues and priorities of the disability community."

Section 504 bars discrimination against qualified individuals because of their disability in programs that get federal funding or are run by federal agencies.

HHS wants to update and clarify the rules in several areas that aren't covered in the current regulations to make sure the rules are consistent with other laws like the Americans with Disabilities Act, the Americans with Disabilities Amendments Act, and changes to the Rehabilitation Act, and significant legal decisions.

This Notice of Proposed Rulemaking (NPRM) clarifies how Section 504 applies. If enacted, the proposed rule:

- Ensures that medical decisions don't depend on stereotypes or judgments about people with disabilities.
- Stops medical practices from scoring a person with a disability as less valuable than a person without a disability.
- Clarifies accessibility requirements for making websites, mobile apps, and kiosks.
- Sets enforceable standards for making medical equipment accessible.
- Clarifies what is required in HHS-funded child welfare programs.
- Stops using value assessment methods that devalue life extension for people with disabilities when deciding who gets access to benefits and services.
- Clarifies the need to provide services in the most integrated setting that suits people with disabilities.

While the Department is working on these rules, the current rules are still in effect. If you think someone was discriminated against because of their race, color, national origin, sex, age, or disability, you can file a complaint online with OCR at https://www.hhs.gov/civil-rights/filing-a-complaint/index.html.

HHS encourages everyone to share their thoughts on these proposed rules through https://www.regulations.gov/.

Public comments on the NPRM are welcome for 60 days after the rules are published in the Federal Register.

To learn more about these rules, you can check the Federal Register for additional information at https://www.federalregister.gov/public-inspection/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities.

A fact sheet on the NPRM is available at: https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/fact-sheet/index.html.

HHS will host a webinar on the NPRM on September 11, 2023, at 1:00 p.m.— 1:45 p.m. Eastern Time. You must register in advance to participate: https://hhsacl.zoomgov.com/webinar/register/WN_cbLO2lobQzecAJBkLKbP_A.

HHS will conduct a Tribal consultation meeting on October 6, 2023, from 2:00 p.m. to 4:00 p.m. Eastern Time. You must register in advance to participate: https://www.zoomgov.com/meeting/register/vJIsceGqpzsjEwi5AQ8pvdIholm7Xp4hwLs.

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About The California State Council on Developmental Disabilities: *The California State Council on Developmental Disabilities (SCDD) advocates, promotes, and implements policies and practices that achieve self-determination, independence, productivity, and inclusion in all aspects of community life for Californians with developmental disabilities and their families. For more information about SCDD visit www.scdd.ca.gov.*

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FOR IMMEDIATE RELEASE
September 7, 2023

Contact: HHS Press Office
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HHS Issues New Proposed Rule to Strengthen Prohibitions Against Discrimination on the Basis of a Disability in Health Care and Human Services Programs

Significant updates to Section 504 of the Rehabilitation Act rule 50 years after the law was enacted to advance equity and bolster protections for people with disabilities

The Biden-Harris Administration is taking further action on its commitment to promote access to health care and human services for persons with disabilities. Today, the U.S. Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), announced a proposed rule that prohibits discrimination on the basis of disability. The rule, Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance, updates critical provisions that help persons with disabilities access health and human services under Section 504 of the Rehabilitation Act of 1973. The rule, originally published in 1977, advances the promise of the Rehabilitation Act and helps to ensure that people with disabilities are not subjected to discrimination in any program or activity receiving funding from HHS just because they have a disability.

“It’s 2023, yet for many Americans accessing basic health needs is still challenging. Some persons with disabilities may have to drive hours to get an accessible mammogram or receive the benefit and advancements of our health care system. This historic proposed rule will advance justice for people with disabilities and help ensure they are not subjected to discrimination under any program or activity receiving funding from HHS just because they have a disability,” said Secretary Xavier Becerra. “We celebrate the inclusion and access promoted by this landmark civil rights law for people with disabilities, by taking action in this proposed regulation to clarify and strengthen the protections afforded by Section 504, reflecting over fifty years of advocacy by the disability community.”

“While we have made significant progress since Section 504 was signed into law nearly 50 years ago, there is more work for us all to live up its promise to the American people,” said HHS Office for Civil Rights (OCR) Director Melanie Fontes Rainer. “Today’s rule is long overdue and a major step forward in the fight to ensure that people with disabilities are not excluded from or discriminated against in health care and social services across the United States. Once again, the Biden-Harris Administration is making clear that we must do better and stand up to improve equitable access to health care, free of discrimination.”

“Freedom from disability-based discrimination is a civil right—and in health and human services programs it can be a matter of life and death,” said HHS General Counsel Samuel Bagenstos. “My office has been privileged to support the Office for Civil Rights as it worked to propose the most comprehensive update to our regulations implementing Section 504 since then-Secretary Califano signed the original 504 regulations in 1977.”

“The COVID-19 pandemic shone a spotlight on the discrimination that too many people with disabilities continue to face, from denial of medical treatment due to ableism, to inaccessible medical equipment and websites, to having no choice but to receive services in institutional settings,” said Alison Barkoff, who leads the Administration for Community Living. “ACL is pleased to have collaborated with the Office for Civil Rights to ensure the rule addresses the most pressing issues and priorities of the disability community.”

Section 504 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. Since the law was enacted, major legislative and judicial developments have shifted the legal landscape of disability discrimination under Section 504.

HHS is proposing to amend the regulations to update them and clarify obligations in several crucial areas not explicitly addressed in the current regulations, and to improve consistency with the Americans with Disabilities Act, the Americans with Disabilities Amendments Act, amendments to the Rehabilitation Act, and significant case law.

This Notice of Proposed Rulemaking (NPRM) clarifies the application of Section 504 to several critical areas. The proposed rule:

- Ensures that medical treatment decisions are not based on biases or stereotypes about individuals with disabilities, judgments that an individual will be a burden on others, or beliefs that the life of an individual with a disability has less value than the life of a person without a disability;
- Clarifies obligations for web, mobile, and kiosk accessibility;
- Establishes enforceable standards for accessible medical equipment;
- Clarifies requirements in HHS-funded child welfare programs and activities;
- Prohibits the use of value assessment methods that place a lower value on life-extension for individuals with disabilities when that method is used to limit access or to deny aids, benefits, and services.
- Clarifies obligations to provide services in the most integrated setting appropriate to the needs of individuals with disabilities.

While the Department is undertaking this rulemaking the current regulation is in effect. If you believe that you or another party has been discriminated against on the basis of race, color, national origin, sex, age, or disability, visit the OCR complaint portal to file a complaint online at: https://www.hhs.gov/civil-rights/filing-a-complaint/index.html <https://www.hhs.gov/civil-rights/filing-a-complaint/index.html>.

HHS encourages all stakeholders to submit comments through regulations.gov.

Public comments on the NPRM are due 60 days after publication of the NPRM in the Federal Register. The NPRM may be viewed or downloaded at the Federal Register:

https://www.federalregister.gov/public-inspection/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities <https://www.federalregister.gov/public-inspection/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities>

A fact sheet on the NPRM is available at: https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/fact-sheet/index.html <https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/fact-sheet/index.html>

The Fact Sheet is available in the following languages: