

Disability Nondiscrimination in Health Care and Community Life During the COVID-19 Pandemic

Disabled people face multiple harms during the COVID-19 pandemic. People who use personal care attendants from outside their homes cannot fully self-isolate, and they may face dangerous gaps in attendant care caused by staffing shortages. Some individuals with disabilities are more vulnerable to contracting COVID-19 and, if they do, may get more sick and have a higher chance of dying. To make matters worse, COVID-19 treatment policies published by states and health care institutions advocate for the “rationing” of care and equipment, and many discriminate explicitly and implicitly on the basis of disability.

The lives of people with disabilities are as equally worthy and valuable as those of people without disabilities. Federal and state laws prohibit disability discrimination. Under the law, people with disabilities must have an equal opportunity to stay safe and to receive life-sustaining treatment during the COVID-19 pandemic.

Overview

Q1: What disability rights laws apply to hospitals, health care providers, health plans, and insurers during the COVID-19 pandemic?

A1: Federal and state laws prohibiting disability discrimination apply to hospitals, health clinics, health care providers, public and private health care insurers, and health plans during the COVID-19 pandemic.¹ These laws include the Americans with Disabilities Act,² Section 504 of the Rehabilitation Act,³ Section 1557 of the Affordable Care Act,⁴ California’s Unruh Civil Rights Act,⁵ and Section 11135 of the California Government Code.

These laws apply to all health care entities experiencing a medical equipment, bed, medication, or staffing shortage during the COVID-19 pandemic. The laws also apply to state policies about how resources should be allocated in the event of shortages.

Q2: What do these laws require?

A2: Under these federal and state laws, **qualified individuals with disabilities** may not be **discriminated against** on the basis of disability by hospitals, health clinics, health care providers, public and private health care insurers, and health plans. Qualified individuals with disabilities are entitled to **reasonable modifications** and **effective communication** they need to equally access health care. Individuals with disabilities are entitled to receive health care in a **space that is accessible** to people with disabilities.

Q3: What is considered a “**disability**” under these laws?

A3: Many mental and physical conditions, including chronic health conditions that are actual or perceived, are disabilities under these laws. Some examples of disabilities are deafness, blindness, intellectual disability, developmental disabilities, mobility impairments, autism, cancer, cerebral palsy, diabetes, epilepsy, muscular dystrophy, multiple sclerosis, neuromuscular conditions like ALS and spinal muscular atrophy, HIV, depression, bipolar disorder, post-traumatic stress disorder, traumatic brain injury, obsessive compulsive disorder, and schizophrenia.⁶ Many higher-weight individuals are protected by disability rights laws, as well as local height and weight ordinances.⁷

Q4: What does it mean to be a “**qualified**” individual with a disability in the context of lifesaving health care during the COVID-19 pandemic?

A4: All people – including all people with disabilities – are qualified to receive lifesaving care,⁸ unless there is objective medical evidence showing that the person will not survive COVID-19, even with treatment, or that the COVID-19 treatment is contra-indicated.

Disability Nondiscrimination and Medical Rationing During COVID-19

Q5: What does disability nondiscrimination mean in the context of hospital triage and medical rationing?

A5: Disability nondiscrimination in the context of hospital triage and medical rationing means eliminating stereotype, bias, and unfair assumptions about people with disabilities and their ability to benefit from treatment. Health care entities must make an individualized, objective, and evidence-based assessment of whether the person can benefit from the care and survive the COVID-19 virus with treatment. The ability to benefit from

treatment and survive is not the same as meeting some standard of “health” or living without chronic symptoms or needs.

The fact that an individual with a disability requires extensive support in activities of daily living, uses augmentative or alternative communication, must adhere to a complex treatment regimen, uses a wheelchair, or experiences a psychiatric disability is not relevant to a medical analysis of whether that individual can respond to and benefit from treatment.

Treatment allocation decisions must not be based on the assumption that people with disabilities experience a lower “quality of life” or that their lives are not worth living.

Assumptions may not be made about who is immunosuppressed, including individuals with HIV/AIDS, without an individualized and evidence-based review of each patient, with any modifications or supports such as medications.

Q6: What about health care rationing schemes that make decisions based on particular disabilities or **diagnoses**?

A6: Health care entities must make an individualized, evidence-based assessment of whether the person can benefit from care. The fact that a patient has a particular diagnosis, such as intellectual disability, autism, cystic fibrosis, diabetes, spina bifida, spinal muscular atrophy, schizophrenia, or traumatic brain injury, is not a legal reason for denying care or making that person a lower priority to receive treatment.⁹ Health care providers must not assume that any specific diagnosis or disability automatically indicates a poor prognosis for near-term survival or an inability to respond to and benefit from treatment.

Q7: What about health care rationing schemes that make decisions based on “**life expectancy**” or “**life years**”?

A7: Consideration of life expectancy or “life years” as a basis for exclusion is a form of illegal discrimination when it screens out people who are thought to have a shortened life expectancy based on their disability.¹⁰ People with disabilities regularly outlive the prognoses that doctors ascribe to them, often by decades. Moreover, having people with various statuses, including disabled people and older adults, is valuable and essential to our society, even if some people do not live as long. People with disabilities make unique contributions – including to developing the systems of care we need during a public health crisis.

Q8: What about health care rationing schemes based on point systems like the “**SOFA**”?

A8: Policies and guidelines that are based on “objective” point systems or algorithms can function to discriminate on the basis of disability. For example, the Sequential Organ Failure Assessment (SOFA) standards may discriminate if people with disabilities, including those who use ventilators regularly, start with a higher baseline score due to pre-existing conditions. SOFA standards may also misconstrue disability-related characteristics. A person with a speech disability could receive a higher SOFA score if they cannot give a verbal response. Many of these systems were developed and validated through observation of patients without disabilities, or rely upon data that is outdated or influenced by unconscious bias.¹¹

Q9: What about health care rationing schemes that make decisions based on the assumption or fact that a person will need **greater resources** during or after their hospitalization?

A9: Treatment allocation decisions may not be made based on the fact that a person’s disability will require the use of greater resources, including equipment, intensity of services, or duration of treatment, either in the short term or long term.

Q10: What about people who use **ventilators in their daily life**?

A10: Individuals with disabilities who use ventilators in their daily lives are entitled to continue to use this customized personal equipment if they receive COVID-19 treatment at a hospital,¹² so long as proper steps can be taken to prevent the spread of the virus. Doctors and triage teams may not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with symptoms of COVID-19.

Reasonable Modifications and Effective Communication in Health Care

Q11: What are **reasonable modifications** in health care?

A11: Under the law, hospitals, health clinics, and other health care providers are required to make reasonable modifications in policies, practices, and procedures when a disabled person needs them to stay safe and to have equal access to care.¹³ Reasonable modifications must be made when a person with a disability needs them in order to have an equal opportunity to access testing or to benefit from treatment for COVID-19.

Reasonable modifications may include permitting a disabled patient to bring a family member, personal care attendant, communicator, or other helper to the hospital with them.¹⁴ The hospital should allow this unless the accompanying individual is sick themselves, and provided that proper steps can be taken to prevent the spread of the virus.

Additional examples of reasonable modifications include:

- Permission to bring an assistance animal to the hospital.¹⁵
- Permission to bring and use needed supplies and medical devices at the hospital, like a ventilator or wheelchair,¹⁶ provided that proper steps can be taken to prevent the spread of the virus.
- **Effective communication**, such as information in simple words, Brailled or large font documents, and communication using an ASL interpreter.
- Additional time in an ICU bed or on a ventilator, if needed to recover due to the compounding effects of an individual's pre-existing disability and COVID-19 infection.
- Information and supports to access follow-up care.

Q12: What is **effective communication** in health care?

A12: Under law, hospitals, health clinics, and other health care providers are required to ensure effective communication.¹⁷ This means that health care providers must ensure that communications with patients with disabilities, and with any family members or companions with disabilities, are as effective as communications with others. If needed for effective communication, health care providers must provide services such as sign language interpreters, real-time captioning (which is also known as CART), written materials, readers, accessible formats such as large font or an electronic format for written information, and information in simple words or pictures.¹⁸ Providers must give priority to the patient's preferred manner of communication.

Providing effective communication to individuals with disabilities who are patients or companions of patients is critical to ensuring compliance with federal law. Without effective communication, the patient's autonomy and ability to participate in their care is taken away and doctors risk substituting misplaced assumptions and biases about the individual with a disability in place of verifiable information and medical history.

Accessible Spaces and Equipment.

Q13: What does physical accessibility mean for health care facilities?

A13: Health care providers and hospitals cannot offer people with disabilities equally effective health care unless their facilities and diagnostic and treatment equipment is fully useable by people with mobility, strength, or coordination disabilities, and people with various body types, shapes, and functional capacities. COVID-19 testing and treatment sites should be offered in physically accessible locations. Physical accessibility includes such features as:

- Entrance ways and paths that are free of steps, elevation drops, cracks, or obstructions.
- Doorways that can be opened automatically or are not very heavy to open.
- Elevators in multi-story buildings (except for some historical buildings) .
- Clear direction signage, including Braille on elevator buttons.
- Sufficient space in passages, waiting areas and treatment rooms for a wheelchair to turn around.
- Height-adjustable exam tables and beds, lifts that support an individual to transfer from a wheelchair or mobility device to a diagnostic/treatment surface, toilet, or tub, with or without human assistance from the provider.
- Bathrooms that are equipped with grab bar in the toilet area, dispensers that can be reached by people using wheelchairs, and sinks with open space below.
- Accessible parking spaces if the facility makes a parking lot or structure available to patients.

Obligations of State and Local Governments During COVID-19

Q14: What are the obligations of state and local governments during COVID-19?

A14: During COVID-19, state and local governments have an obligation to keep people with disabilities as safe as everyone else.¹⁹ This means that they must take affirmative steps to keep disabled people supported and safe in their homes. Governments must also affirmatively state that disability discrimination is unlawful, including during the COVID-19 crisis, and take action when health care providers or other covered entities are not complying with disability nondiscrimination law.

Q15: How can state and local governments keep people with disabilities equally safe in their homes during COVID-19?

A15: State and local governments can keep disabled people safe in their homes by taking steps to ensure that people have access to the devices, supplies, personal care attendants (PCAs), and they need. These include:

- Ensure that people who rely on personal care attendants have ready access to emergency back-up attendants.
- Ensure uninterrupted access to medical devices and supplies, including back-up devices and needed maintenance and repairs.
- Ensure that personal care attendants, home health care providers, and disability services providers have personal protective equipment (PPE).
- Provide PCAs with training, sick time, hazard pay, PPE, and one-time recruitment incentive payments.
- Ensure that disabled people and their PCAs receive appropriate services and supervision from primary care, specialist, and therapy providers via telehealth or home health visits.
- Ensure the availability of 90 day supplies of medically-necessary medications and disposable medical equipment without prior authorization and other utilization measures.
- Ensure the availability of accessible non-emergency transportation options for disabled people who must leave their home for urgent appointments.
- Consider emergency-based changes to scope of practice rules to allow PCAs and other para-professionals to engage in paramedical tasks and work at the top or beyond their existing professional competencies.

Obligations of Hospitals and Health Care Providers During COVID-19

Q16: What steps should hospitals and health care providers take to avoid discriminating against people with disabilities during the COVID-19 crisis?

A16: Hospitals, health clinics, and other health care providers should take all affirmative steps available to them avoid reaching a point of scarce resources that might trigger a need to ration emergency and intensive care. These include providing services such as telehealth and home health care to allow people with disabilities and older persons to safely shelter-in-place over a prolonged period. These include collaboration with regional partners in emergency and intensive care units.

Hospitals and health care providers should communicate to public, staff, and contractors a commitment to nondiscrimination, including on the basis of disability. Any policy documents or protocols used or adopted by a hospital or other health care provider for use during the COVID-19 crisis should affirmatively state that disability discrimination is prohibited by law.

Q17: What else is important about policy documents used or adopted by health care providers for use during the COVID-19 crisis?

A17: Policy documents should not direct or endorse disability discrimination in the allocation of scarce resources during the crisis, nor rely on objective criteria that tend to screen out people with disability from COVID-19 related care.

Such policies should direct health care entities to conduct a thorough, individualized, and evidence-based review of each patient to determine the individual's ability to respond to treatment and to survive in the immediate short-term. Wherever possible, protocols should include speaking to the individual to verify his or her disability-specific information so that triage decisions can appropriately factor out the impact of stable chronic conditions from the immediate functional impacts of the virus. Such policies should not endorse decision-making about the provision and allocation of health care based on life expectancy (beyond immediate survival of the COVID-19 virus), "life years," perceived quality of life, and/or the existence of particular disabilities and diagnoses.

Any policy must include an appeal process that is both explained and available to all patients. Patients considering an appeal should be referred to Disability Rights California.

These important documents must be made publicly available and widely distributed to stakeholders, including the disability community, in order to ensure accountability.

Q18: What about the training of health care providers?

A18: There is a long history and present of disability discrimination in medical care.²⁰ Doctors and triage teams must not assume that they are free from conscious or unconscious disability bias in making critical life and death health care decisions.

Providers or triage teams involved in developing or applying policies on how to allocate scarce resources or apply protocols during the coronavirus pandemic must undergo or have undergone training on avoiding discrimination, including disability discrimination.

Endnotes

¹ U.S. Dep't of Health & Hum. Srvs., *BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)* (Mar. 28, 2020) ("OCR Guidance"), at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>; Departments of Health Care Services (DHCS), Public Health (CDPH), and Managed Health Care (DMHC), *Guidance Relating to Non-Discrimination in Medical Treatment for Novel Coronavirus 2019 (COVID-19)* (Mar. 30, 2020) ("California Guidance"), at <https://www.dhcs.ca.gov/Documents/COVID-19/Joint-Bulletin-Medical-Treatment-for-COVID-19-033020.pdf>.

² 42 U.S.C. §§ 12131, 12132, 12181(7)(F), 12182(a).

³ 29 U.S.C. § 794.

⁴ 42 U.S.C. § 18116.

⁵ Cal. Civ. Code § 51 et seq.

⁶ 28 C.F.R. § 35.108(d)(2)(iii).

⁷ NoBodyIsDisposable, *Where Higher Weight May Be Protect*, at <http://nobodyisdisposable.org/know-your-rights/#protected> (listing jurisdictions and citing *Taylor v. Burlington N. R.R. Holdings, Inc.*, 193 Wash. 2d 611, 617, 444 P.3d 606, 609 (2019)).

⁸ 42 U.S.C. § 12131(2); *see also* *Silva v. Baptist Health S. Fla., Inc.*, 139 F. Supp. 3d 1319, 1336 (S.D. Fla. 2015) (finding "no dispute" that deaf patient was "a qualified individual"); *Aikins v. St. Helena Hosp.*, 843 F. Supp. 1329, 1338 (N.D. Cal. 1994) (finding that spouse of patient was "qualified" individual); *Loeffler v. Staten Island Univ. Hosp.*, 582 F.3d 268, 275 (2d Cir. 2009) (finding no dispute that deaf patient and deaf wife were "otherwise qualified" individuals with a disability).

⁹ 42 U.S.C. §§ 12132, 12182; *see also* *Bragdon v. Abbott*, 524 U.S. 624, 648-55 (1998) (reviewing and remanding claim under ADA alleging discrimination in health care based on HIV); *United States v. Asare*, No. 15 Civ. 3556, 2018 U.S. Dist. LEXIS 93023, at *17 (S.D.N.Y. June 1, 2018) (refusal to provide cosmetic surgery services to patients taking antiretrovirals was impermissible under the ADA).

¹⁰ *Id.*; 28 C.F.R. §§ 35.130(b)(8), 36.204; *Guckenberger v. Boston Univ.*, 974 F. Supp. 106, 134-37 (D. Mass. 1997) ("This tend-to-screen-out concept ... makes it discriminatory to impose policies or criteria that, while not creating a direct bar to individuals with disabilities, diminish an individual's chances of such participation."); *cf.* *Bates v. UPS*, 511 F.3d 974, 994 (9th Cir. 2007) (hearing test had the effect of discriminating on the basis of disability and/or screened out the class of deaf employees); *Hendricks-Robinson v. Excel Corp.*, 154 F.3d 685, 699 (7th

Cir. 1998) (finding that criterion of “physical fitness ... tends to screen out, whether intentionally or unintentionally, disabled employees”).

¹¹ Amitha Kalaichandran, “AI Could Predict Death. But What If the Algorithm Is Biased?” *Wired* (Apr. 21, 2019), at <https://www.wired.com/story/ai-bias-predict-death/>.

¹² See *Jardina v. Dep’t of Pub. Safety & Corr. Servs.*, No. JKB-16-1255, 2019 U.S. Dist. LEXIS 65429, at *26, *27 (D. Md. Apr. 17, 2019) (denying motion for summary judgment in disability discrimination claim based on denial of assistive device while in administrative segregation); *Peters v. Butler*, No. 16-cv-00382-JPG, 2016 U.S. Dist. LEXIS 47770, at *3, *9 (S.D. Ill. Apr. 8, 2016) (permitting disability discrimination claim to proceed where plaintiff’s wheelchair was confiscated upon transfer to a new facility); *Givens v. Cty. of Sacramento*, No. 2:15-cv-0720 JAM KJN PS, 2016 U.S. Dist. LEXIS 154427, at *12 (E.D. Cal. Nov. 7, 2016) (denying motion to dismiss where plaintiff alleged denial of request for cane during arrest and hospitalization).

¹³ 28 C.F.R. § 35.130(b)(7).

¹⁴ 42 U.S.C. § 12182(b)(2)(A)(ii); 28 C.F.R. § 35.130(b)(7); see also New York Department of Health, Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation, April 10, 2020, at 1-2, at https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_041020-002.pdf (permitting support person who is essential to the care of the patient); Rush Hospital COVID-19 Patient and Visitor Updates, at <https://www.rush.edu/patients-visitors/covid-19-resources/coronavirus-patient-visitor-updates-covid-19-patient> (“If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection.”); *Jett v. Brookhart*, No. 17-cv-517-DRH, 2017 U.S. Dist. LEXIS 153221, at *4, *7 (S.D. Ill. Sep. 20, 2017) (permitting plaintiff to proceed with claims of disability discrimination based on denial of attendant to accommodate disability including to access health care); *Anderson v. Franklin Inst.*, 185 F. Supp. 3d 628, 651 (E.D. Pa. 2016) (finding it reasonable for defendant to modify its policies and practices to permit free admission of PCA to assist severely disabled client).

¹⁵ *Matheis v. CSL Plasma, Inc.*, 936 F.3d 171, 174 (3d Cir. 2019) (reversing summary judgment in favor of plasma donation facility that denied disabled individual’s use of a service animal); *Tamara v. El Camino Hosp.*, 964 F. Supp. 2d 1077, 1088 (N.D. Cal. 2013) (granting preliminary injunction requiring hospital to assess under ADA standards whether to allow a disabled patient’s service dog on psychiatric ward).

¹⁶ See n. 12, *supra*.

¹⁷ 28 C.F.R. § 35.160.

¹⁸ See COVID-19 Communication Rights Toolkit, at <https://communicationfirst.org/covid-19/>. ¹⁹ See *Brown v. Dep’t of Pub. Safety & Corr. Servs.*, 383 F. Supp. 3d 519, 559 (D. Md. 2019) (“Title II and Section 504 require Defendants to provide safe housing to disabled and non-disabled inmates alike.”); *Arenas v. Georgia Dep’t of Corr.*, No. CV416-320, 2018 WL 988099, at *8 (S.D. Ga. Feb. 20, 2018) (finding that incarcerated plaintiff stated claim under ADA by alleging that he was denied access to safe housing assignment); *Cox v. Mass. Dep’t of Corr.*, 18 F. Supp. 3d 28, 46 (2014) (finding that plaintiff stated claim under ADA by alleging that he