

Section 5. Self-Advocacy Tools and Resources

Nearly five decades since the passage of Section 504, and now three decades since the passage of the ADA, the overwhelming number of healthcare providers in the country still do not fully comply with their federal nondiscrimination mandates as it pertains to persons with disabilities. Two hard truths:

- the first: the overwhelming number of healthcare providers conduct a cost-benefit analysis when determining whether to comply with their federal nondiscrimination mandates as it pertains to persons with disabilities; and
- the second: when considering why healthcare providers have not fully embraced their federal nondiscrimination mandates, persons with disabilities are partly to blame as we have not exercised our legal rights under Section 504 and the ADA to compel healthcare providers to comply with those nondiscrimination mandates.

A. Your Rights

Both the ADA and Section 504 include a private rights of action, meaning that persons with disabilities can, individually, enforce the ADA and Section 504 by taking action on their own, whether that means of filing a complaint with the Department of Justice, the Department of Health and Human Services Office of Civil Rights or filing a lawsuit in federal district courts. To assert your legal rights requires that you know what your rights are to accessible healthcare. In a nutshell, for persons with paralysis and mobility disabilities, under the ADA and Section 504 you have the right to:

- receive reasonable assistance. Reasonable assistance from a healthcare provider's staff to: complete, in a private manner, required paperwork upon checking-in to a healthcare provider's office for an appointment, whether scheduled or unscheduled; retrieving insurance and identification cards; removing outerwear upon arrival and assistance with putting on outerwear upon termination of the appointment or visit; and assistance changing into an examination gown, if required.

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- elect to remain in your wheelchair for an examination, or to be transferred. If a thorough examination can only be provided while a person is on an examination table or in examination chair, then – unless you elect to remain in your wheelchair – you have a right to be examined while on the examination table or examination chair, as appropriate. For example, a complete physical examination, checking for pressure sores on your lower extremities, conducting pelvic examination, gynecological examination, prostate examination, etc., can only be provided if a patient is laying down on an examination table.
- choose the method by which you are transferred. If you elect to be transferred from your wheelchair onto an examination chair, examination table or diagnostic equipment, then you should choose the manner by which you are transferred – state your preference, transfer board, Hoyer lift, physically lifted or some other form of assistance. Note, you do not have an absolute right to be physically lifted. Healthcare providers can decline to physically lift you if they do not have personnel who are trained in safe patient lifting techniques.
- be weighed utilizing a wheelchair accessible weight scale. You have the right to be weighed, and you also have the right to refuse to be weighed. If you elect to be weighed, the provider should have available a wheelchair accessible weight scale. A wheelchair accessible weight scale is a weight scale with a platform that allows you to roll on to obtain the weight of you and your wheelchair together. An accurate weight measurement is than obtained by subtracting the weight of your wheelchair. If you do not know the weight of your wheelchair, then the healthcare provider should remove you from your wheelchair and weigh the chair separately. It is important to note that some Hoyer lifts have integrated weight scales as do some patient beds. Those are alternative methods by which to attain your weight measurement. Absent a wheelchair accessible weight scale, providers will either use a weight measurement from a previously recorded visit – which may or may not be accurate – they may ask you for your weight or they may guess at your weight.
- be accompanied by a service animal. If you have a service animal, your service animal can accompany you to areas of a healthcare facility where the public is invited to go. For example, in all public areas, including waiting rooms, cafeteria, gift shops, restrooms, etc. in addition you may be accompanied by your service animal into the examination and treatment rooms. A healthcare facility for safety, including infectious control purposes, may refuse to have you accompanied by your service animal in operating rooms, intensive care units, burn units, or other areas containing equipment critical for life-support.
- be treated in an examination or treatment room that is accessible. You have a right to be examined or received treatment in accessible examination or treatment room. An accessible examination room has a door wide enough for you to enter with your mobility device, with enough space within the examination room for you and, if required, lift

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equipment; and sufficient space for side transfers. The examination room should also have a height adjustable examination table to facilitate either your independent transfer or transfer utilizing lift or transfer equipment, or to facilitate a safe transfer if physically lifted.

- be assigned to an accessible patient room. If hospital admission is required, you have a right to be assigned to an accessible patient room. An accessible patient room has a door wide enough for you to enter, sufficient clearance for you to maneuver in your mobility device, sufficient room for your mobility device and lift equipment, and with an accessible bathroom and shower. An accessible bathroom has a door wide enough for you to enter with your mobility device, a toilet with handrails next to and behind it, a sink with clear floor space, toe space and with pipes insulated and faucets that can be operated without tight grasping, pinching or twisting of the wrist. An accessible shower includes either a built-in seating area or minimum to zero threshold roll in shower to be used with the shower chair.
- file a complaint or provide feedback to the healthcare provider's Disability Access Coordinator, ADA coordinator or 504 coordinator. A healthcare provider should have someone designated specifically to ensure the provider's compliance with the federal nondiscrimination mandates under the ADA or Section 504. That person may have the title of ADA coordinator, 504 coordinator, Disability Access Coordinator or a different title. You have the right if you encounter accessibility issues to file a complaint with that person who then has an obligation to investigate and address your concerns. There is no specific time required to file that complaint, however, it should be done no later than two weeks after your visit to the healthcare provider so that the facts remain clear in your mind as well as to facilitate their investigation of your concerns. The healthcare provider may have an intake form or other method to facilitate your ability to file a complaint on their website, and if not, request the email address for the ADA, 504 Or Disability Access Coordinator and email to them your complaint or write them a letter the old-fashioned way. If you need assistance in addressing accessibility issues with the healthcare providers office, be aware that each state has a Protection and Advocacy organization which is essentially a nonprofit organization that advocates on behalf of, and protects the rights of, persons with disabilities. The Protection and Advocacy organization is mainly comprised of lawyers who will assist you in investigating and addressing complaints of disability-based discrimination. Note that Protection and Advocacy organizations do not accept every case of discrimination, but to also provide information and referral services in the event they are not able to assist you. Also, Centers for Independent Living are nonprofit organizations located in each state that advocate for the rights of persons with disabilities and empower them to live self-defined independent lives. Centers for Independent Living often have working relationships with their local healthcare providers and can assist in addressing healthcare discrimination issues.

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- file a complaint with your state’s Attorney General’s office, human rights commission, the Department of Justice or the Department of Health and Human Services. Each state Attorney General’s office may have a disability rights bureau or a specific department that you can address your complaint against the healthcare provider either by submitting the complaint online, via email or in a written letter. There typically is a time limitation by which to file your complaint with your state Atty. Gen.’s office, which may be anywhere between 120 days and 300 days after the date of the discrimination occurred. For filing the complaint with the Department of Justice or the Department of Health and Human Services the time limit by which to file your complaint is 180 days after the occurrence of the discrimination. If your state, county or city has a human rights commission, complaints may be filed with that commission either online, via email or by a written letter, and there is usually a specified timeframe by which to file the complaint which can be anywhere between 120 days and 300 days after the occurrence of the discrimination. As each jurisdiction is different, you should inquire with the appropriate office or agency as to your filing deadlines.

B. Available Resources

- To better understand your rights to accessible healthcare:

Accessible Healthcare for Persons with Paralysis and Mobility Disabilities, a three-part webinar series conducted in [July](#), [August](#), [September](#) 2020, hosted by the Reeve Foundation.

- To locate your local Protection and Advocacy Organization:

Protection and Advocacy Systems are organizations comprised mainly of lawyers in each state to protect persons with disabilities by empowering them and advocating on their behalf. Beyond litigation, protection and advocacy systems often serve as referral sources, as well as technical and training assistance to organizations. For directory of protection and advocacy systems in each state, see the National Disability Rights Network, the nonprofit membership organization for Protection and Advocacy Systems. <https://www.ndrn.org/about/ndrn-member-agencies/>

- To locate a nearby Center for Independent Living:

The Independent Living Research Utilization program has a directory of the over 400 Centers for Independent Living in the United States. The directory can be

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found at: <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

- To file a complaint with a State Attorney General's office:

State Attorneys General are the top legal officers in each state or territory, and most, if not all, have specific divisions established to protect the rights of persons with disabilities within their state. For a directory of State Attorneys General, visit USA GOV, at <https://www.usa.gov/state-attorney-general>

- To file an online complaint with the Department of Justice:

Filing a Americans with Disabilities Complaint with the Department of Justice, online complaint form: https://www.ada.gov/filing_complaint.htm

- To file an online complaint with the US Department of Health and Human Services:

Filing a Complaint under Section 504 of the Rehabilitation Act of 1973 with the US Department of Health and Human Services, Office for Civil Rights, Complaint Portal Assistant, available at: <https://ocrportal.hhs.gov/ocr/smartscreen/main.jsf>

- To identify settlements of disability-based discrimination between the Department of Justice and healthcare providers:

Department of Justice, Barrier Free Healthcare Initiative, enforcement actions, available at: <https://www.ada.gov/usao-agreements.htm>

- To learn more about healthcare providers obligations to provide accessible healthcare services for persons with paralysis and mobility disabilities:

Americans with Disabilities Act, Access to Medical Care for Individuals with Mobility Disabilities, available at: https://www.ada.gov/medcare_mobility_ta/medcare_ta.htm

- To learn more about Disability Etiquette and tips on interacting with persons with disabilities:

United Spinal Association, Disability Etiquette, Tips on Interacting with People with Disabilities. Available at: <https://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>

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- To learn more information about your rights and healthcare providers' obligations relating to service animals:

Department of Justice, Civil Rights Division, Disability Rights Section, Frequently Asked Questions about Service Animals and the ADA. Available at: https://www.ada.gov/regs2010/service_animal_qa.pdf

Department of Veteran Affairs, Veterans Health Administration, VHA Directive 1188 (1), August 26, 2015, Amended on April 25, 2019. Animals on Veterans Health Administration Property. Available at: https://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=3138

- Information relating to Persons with Disabilities and COVID-19

Access Living of Metropolitan Chicago, a Center for Independent Living. COVID-19 Resources for the Disability Community. Available at: <https://www.accessliving.org/our-services/covid-19-resources-for-the-disability-community>

Administration for Community Living. Coronavirus 2019 (COVID-19): Information for Older Adults and People with Disabilities. Available at: <https://acl.gov/COVID-19>

American Association on Health and Disability. Resources for People with Disabilities on COVID-19. Available at: <https://www.aahd.us/covid-19/>