



AASPIRE

Healthcare Toolkit

Your Rights in Healthcare: Equal Access

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Your Rights in Healthcare: Equal Access

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1 What is this topic about?

This topic is about getting equal access to healthcare. Equal access means having the same opportunity to get quality healthcare as people who are not on the autism spectrum.

The Americans with Disabilities Act (ADA) is the main law that requires equal access to healthcare for people with disabilities, including people on the autism spectrum. This section talks about how the ADA applies to healthcare, how to get accommodations for equal access, and where to find more information about the ADA in healthcare settings.

2 What is the ADA?

The Americans with Disabilities Act (ADA) is a broad law that makes sure people with disabilities are not discriminated against and have equal access to

- employment,
- state and local government services, information, and buildings,

- public transportation,
- privately operated facilities that are open to the public (for example, restaurants, retail stores, hotels and movie theaters, doctors' offices, homeless shelters, and recreation facilities),
- telephone service, including the requirement that telephone companies provide relay service and assistive telecommunications devices for the deaf and hard of hearing.

3 What are "reasonable accommodations"?

Healthcare settings are covered under state and local government services, information and buildings, and under privately operated facilities that are open to the public.

Making healthcare accessible is typically done by providing "reasonable accommodations".

An *accommodation* is a modification or adjustment to something that enable a person with a disability to do something they would not otherwise be able to do.

A *reasonable* accommodation is an accommodation that can be made without causing "undue hardship". Undue hardship is considered "significant difficulty or expense".

Accommodations are not defined in the ADA. It is expected that accommodations will be negotiated on a case-by-case basis. What is "reasonable" is also not defined in the ADA beyond saying it is "feasible" and "plausible" and would not cause "undue hardship." Part of the reason for this vagueness is because what is "reasonable" could change depending on the situation.

An example of an *accommodation* for someone who has a hard time hearing or following quick real-time speech might be hiring someone to provide closed captions.

That accommodation might be *reasonable* if it's requested at a large government-sponsored conference.

But the same accommodation might cause *undue hardship* for a small conference where the cost of hiring someone to provide closed captions would be larger than the entire conference budget.

4 How does the ADA apply to healthcare?

The ADA does not give specific recommendations for how to give people equal access to healthcare. This is because different people have different needs. What helps one person might not help another. Instead the law just requires that facilities and services are accessible, as long as it does not cause "undo hardship." What will cause "undue hardship" will be different depending on where you get your healthcare. For example, a clinic that's part of a large city hospital might have a greater ability to accommodate some needs, for example providing an American Sign Language (ASL) interpreter, than a small, rural practice. A small, rural practice may have a greater ability to accommodate other needs, for example, they may be more able to offer house calls. Healthcare providers may not know about the ADA or understand that it applies to them. Each provider is different, but in general, it is easiest to educate providers about the ADA while discussing your own personal needs for accommodations. Here are some examples of ways that accommodations under the ADA can happen in healthcare. These are just meant to be examples. You might not need these things. Your clinic may also not be able to provide all of them.

4.1 Accessible Buildings / Facilities

The ADA requires that certain buildings (such as state and local government buildings) follow accessibility standards to ensure people with disabilities can

fully access them and the services that happen within them. Most healthcare facilities and buildings are covered under this law. Examples of ways buildings or facilities can be made accessible to people on the autism spectrum are by:

- providing sensory-friendly waiting or examination areas,
- providing maps or assistance navigating buildings,
- making sure mobility devices can access buildings.

4.2 Accessible Communication / Services

The ADA requires healthcare facilities to provide patients and their supporters with services to ensure effective communication between patients and healthcare providers. This includes things like:

- qualified interpreters
- note takers
- real-time computer-aided transcription services or real-time captioning
- written materials
- exchange of written notes
- braille materials
- screen readers
- large print materials

Other examples of ways communication and healthcare services can be made accessible to individuals on the autism spectrum are:

- allowing a service animal or trusted person to be present,
- allowing extra time for communication,

- preparing a schedule of the visit in advance and being communicative of changes,
- requesting healthcare providers use direct, specific language.

The examples given here are just that: examples. If there is something you need in order to make healthcare facilities or communication with healthcare providers accessible to you, discuss it with your healthcare provider. The ADA is open-ended so that lots of different kinds of needs can be met.

5 How do I request ADA accommodations for my healthcare?

If you need accommodations to access healthcare, talk to your healthcare provider or their office staff about your needs.

No one can say for sure how a particular provider will respond to a particular patient's requests for accommodations. However, the following are a few tips that may make your request for accommodations more effective:

- Do not make the request seem like a demand.
- Explain the way(s) that your disability makes it difficult to get good healthcare. Give concrete examples.
- Say that you would like to discuss possible accommodations that could help make visits go more smoothly. (Or that could help you make it to your appointments, or that could help you better follow the providers recommendations, etc.)
- Give some ideas of possible accommodations. Ask if they would be possible or if the provider has other ideas of accommodations that would work well in their clinic or practice.

Sometimes, you may be able to ask for some accommodations before you go to an appointment. Here is an example of a way to request an accommodation from office staff before your visit.

"I am on the autism spectrum and I have a very hard time waiting in busy waiting areas. I get so overstimulated and confused that by the time I go see the doctor, I can no longer pay attention to what he is saying or answer his questions. I would love your help to think about possible accommodations. One idea would be to let me wait in a quiet room until it is my turn. Another would be to let me wait in my car and then call or text my cellphone when it is my turn. Would either of these things work? Do you have any other ideas? I really appreciate your help."

However, more complex discussions of accommodations take time. It is best to schedule an appointment with your provider to talk about a good long-term plan.

Here is an example of a possible way to request accommodations during a visit with a provider:

"I am on the autism spectrum and I sometimes have a hard time with office visits. I often get so anxious or confused that I can't answer questions well or understand recommendations. Could we talk a little about possible accommodations that would make it easier for me to make it through an office visit?" (wait for response.) There are a few things that may help. First, I get really anxious and confused if I don't know what to expect. One thing that might help is to write down a list of things to expect during the visit and then point to each step as we get to it. Is that something that would be possible? Do you have other ideas to help me better understand what to expect during a visit?" (wait for response and discuss ideas)

"Another problem is that I sometimes can't process information quickly. That means that I may not be able to understand what you are saying, think about it, and make a decision as fast as other patients. One idea is to tell me your recommendations, write down the key points, go see another patient, and then come back and let me tell you what I would like to do. Another idea would be to write down the key points, let me think about it at home, and then let me tell you my decision via your secure messaging system. Would either of these ideas work? Do you have other ideas that may help give me extra time to process information?" (wait for response and discuss ideas)

6 What if my healthcare provider does not immediately give me the ADA accommodations I asked for?

Most providers really do want to offer effective healthcare. There may be a number of reasons that a provider does not immediately comply with a request for ADA accommodations:

- They may not understand how your disability affects your healthcare. Try to give very practical examples of how your disability gets in the way of your healthcare. For example, instead of just saying *"I don't like fluorescent lights,"* say, *"I am really sensitive to fluorescent lights. The buzzing and flickering makes it hard for me to focus on what you are saying."*
- They may have perceived your request as an accusation that they did something wrong. Then they may have gotten defensive. It can help if you start your conversation with one of the following sentences to try to set them at back ease:
 - *"I know you are trying to help me."*
 - *"I appreciate your time and your patience with me."*
 - *"I appreciate that you are very busy."*

- *“Sometimes I am very direct, but I would really like to work with you to make visits go more smoothly.”*
- *“I appreciate _____”* (where you fill in the blank with something you honestly do appreciate about your healthcare provider).
- They may not know how to actually give you accommodations. Give them practical examples of what may help.
- They may not be able to do exactly what you ask, and may think that it’s the only option. Make it clear that these are just ideas and you are open to other things that may work better in their practice.
- They may be stressed about time and feel like they don’t have the time to deal with your request for accommodations. Try to make it clear that you respect how busy they are. Work with them to find a better time to talk about your request. Tell them you would like to work with them to find accommodations that can fit into a busy clinic schedule.
- They may get overwhelmed if you make too many requests at once. It is best to highlight just a few accommodations. Focus on the ones you think are going to be more useful.
- They may not be thinking of your requests as ADA accommodations. Many providers think of the ADA as it applies to things like the need for wheelchair ramps, but they may not have ever thought about the ADA as it applies to their own patient care. They may be confusing your requests as “preferences” instead of actual ADA accommodations. Using the word “accommodations” and specifically linking the requests to your disability may help. If not, it may help to educate them about the ADA. But it is best to do so in a non-threatening way. For example, instead of saying, *“The law says you have to give me accommodations,”* you may say, *“The ADA protects my right to have reasonable accommodations in healthcare, and I want to work with you to figure out what would be reasonable in your practice.”*

Getting the right accommodations is likely going to take time. It may take more than one visit to set up the accommodations you need and to find ways to actually make them work. Your accommodations are also likely to change over time. If a provider seems to be open to working with you, have patience and keep trying to figure out what works best. If a provider does not seem willing to work with you, you have the right to go to a different provider. Some providers are never going to work well with some patients. Try to find someone who will.

7 How do I make sure other healthcare providers know about my ADA accommodations?

Encourage your healthcare provider to keep a written list of your accommodations with your records so they and their staff will know your accommodations the next time you need healthcare. You might want to make an Autism Healthcare Accommodations Report for your healthcare provider. Keep a copy of your accommodations report so that you can show it to other providers.

During emergency situations, you might not be interacting with your regular doctor, or you might not be able to communicate your needs. Write down the most important accommodations you need and keep the note in your wallet, bag, purse or something that you are likely to have with you. That way emergency personnel can find it. A PDF form you can download and fill out is available at www.my-healthkey.com.

You may also want to consider getting a medical ID that notes important information about accommodations you need in medical situations. You can get medical IDs online from many places such as www.americanmedical-id.com and <http://www.medicalert.org/>. You can search for "medical id jewelry". Some jewelry stores will also make them. Ask your local jewelry stores.

8 Do I have to tell my healthcare provider about my ASD diagnosis to get accommodations?

If you want to get accommodations under the ADA, you need to disclose your diagnosis to your healthcare provider. This is because the ADA only requires people to make accommodations for individuals who have a documented disability. For more information on how the ADA defines disability see "Are people on the autism spectrum protected by disability rights laws?"

It is sometimes possible to get informal accommodations without disclosing that you have ASD. For example, you might just say, "I have a disability that makes it hard for me to talk on the phone, can we come up with a different way for me to communicate with your office?" Others may be willing to accommodate your needs, and not question why you need them. However, people will not be required to accommodate your needs if you do not share that you have a documented disability. They can refuse and you will not be able to do anything about it legally.

For more information on disclosure see the Disclosure section.

9 Where can I find more information and advice on the ADA?

You can get more information about the ADA, as well as information about other laws that protect the rights of people with disabilities in the section Disability Rights Laws.

Also, here is a comprehensive list of links to resources related to the ADA.

Main ADA page - <http://www.ada.gov>

For more information on the ADA and healthcare - <http://www.pacer.org/publications/ada>
For more a very in-depth legal analysis of the ADA in healthcare, see <http://www.ncbi.nlm>
(note: this article is written in a very academic style)

ADA Centers see <http://adata.org/Static/Home.html>

For a useful questions and answers article on the ADA and healthcare from the Pacer Center: <http://www.pacer.org/publications/adaqa/health.asp>

ADAdata.org has a frequently asked questions page where you can learn more about the ADA. <http://adata.org/faq-page>

Here are direct links to the ADA Centers for each region in the U.S.:

- New England ADA Center - Maine, New Hampshire, Vermont, Massachusetts, Connecticut, and Rhode Island www.NewEnglandADA.org
- Northeast ADA Center - New Jersey, New York, Puerto Rico and the U.S. Virgin Islands www.dbtacnortheast.org
- Mid-Atlantic ADA Center - Delaware, District of Columbia, Maryland, Pennsylvania, Virginia and West Virginia www.adainfo.org
- Southeast ADA Center - Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina and Tennessee www.sedbtac.org
- Great Lakes ADA Center - Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin www.adagreatlakes.org
- Southwest ADA Center - Arkansas, Louisiana, New Mexico, Oklahoma and Texas www.dlrp.org
- Great Plains ADA Center - Iowa, Kansas, Missouri and Nebraska www.gpadacenter.org
- Rocky Mountain ADA Center - Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming www.adainformation.org
- Pacific ADA Center - Arizona, California, Hawaii, Nevada and the Pacific Basin www.adapacific.org
- Northwest ADA Center - Alaska, Idaho, Oregon and Washington www.dbtacnorthwest.org

10 Summary and Tips

The Americans with Disabilities Act (ADA) is the main law that requires health-care settings to be accessible to people with disabilities.

The ADA does not specify how to make healthcare settings accessible but requires that

- Healthcare buildings and facilities are physically accessible.
- Communication with healthcare providers and healthcare services is accessible.
- Modifications to make healthcare accessible do not cause significant difficulty or expense to implement.

Figuring out how to make facilities and communication accessible in a way that works well for everyone is done in a conversation with the healthcare provider or their office staff.

If you need an accommodation for regular healthcare visits, request it from your healthcare provider or their office. For accommodations and communication during emergency situations, carry a note or use a medical ID that has the most important accommodations listed on it.

If you want accommodations under the ADA, you need to tell your healthcare provider about your ASD diagnosis. You may also request accommodations without disclosing your diagnosis, but your healthcare provider or their office may legally refuse your request.