

Health Care Self-Advocacy

The Americans with Disability Act (ADA) of 1990 prohibits discrimination against people with disabilities in several areas. It requires that health care entities provide full and equal access for people with disabilities. Facilities must also make reasonable efforts to accommodate individuals with disabilities.

***You have the right to:**

Reasonable modifications to policies, practices, and procedures.

Below are some examples of potential reasonable modifications you can request:

- Extended appointment times to move around/adjust for exams, or more time to understand information being communicated to you
- Staff assistance to fill out medical forms
- Bring your service animal into the appointment with you
- Have a support person with you

Effective Communication

Effective communication could include any of the communication methods below:

- A sign language interpreter provided by the facility
- Written communication in alternative formats such as large print or Braille
- Plain language to ensure information is easy to understand
- Utilize relay services 711 for speech-to-speech translation services if clinicians are unable to understand patient speech

Accessible Facilities

Accessible Facilities include: accessible parking places, ability to enter, travel and receive health care services. The list below includes examples of accessible features within a facility.

- Parking spaces and entry
- Doors with lever handles
- Wheelchair accessible bathrooms with clear turning space, grab bars, accessible sinks
- Accessible scale
- No objects that protrude more than 4 inches along the routes of travel

- Examination rooms
 - Clear pathways of travel
 - Entry doors that meet minimum clear widths of 32 inches
 - Clear floor and turning space inside the rooms
 - Exam tables that are height adjustable *or* patient lifts
- Treatment procedures – any medical equipment, exams, instruments should be able to effectively treat you or be modified such that you can receive effective treatment.

*This list is not exhaustive. Contact your local ADA Center for more information: 1-800-949-4232. Visit the ADA National Network website: www.ADATA.org.

How to Request Accommodations

When possible, let your health care facility know before your appointment of your request for accommodations. Let the clinic know what your needs are and work together to figure out how your needs will be accommodated.

Some health care facilities may include information about how to request accommodations on their websites. Additionally, many facilities use electronic health care apps* that allow you to enter information about yourself that the clinicians can review in advance of your appointment. **If the electronic health record service is not accessible to you, contact your health care clinic and your local ADA center to discuss the barriers.*

When possible, consider conducting your own proactive accessibility inventory. This could include scheduling a walk-through visit before your actual appointment to figure out what barriers might exist, and what accommodations will be needed.

Getting Ready for Your Appointment

Create an “About Me” worksheet

Create a fact sheet about you that helps your nurses and doctors understand what they should know about you. This can be provided at the beginning of the appointment and can help nurses and doctors better understand your preferences.

What could I include in the “About Me?”

- *Your preferred communication style:* What tools do you use for communication, that the doctor should always direct their attention to you throughout the appointment.

- *Decision-Making*: Let the doctor know if you are your own guardian and health care decision maker. Alternatively, if someone supports you in making health care decisions, state what role they will have in making decisions.
- *The Role of Your Support Person*: If any, tell the doctor how you want the support person to function during your appointment. This may include not directing any conversation to them at all, only asking them for physical assistance as needed, or communicating slowly and clearly to allow that person to take notes.
- Your health care questions for today's appointment.

Choosing a Doctor/Clinic

Before enrolling with a health care provider, ask questions to make sure the health care clinic/doctor is a good fit for you. Ask the clinic about what part of their facility, medical care, equipment is accessible, how they provide accommodations, what experience the health care facility has providing health care to people with disabilities *NOTE: A doctor cannot refuse to serve someone with a disability just because they have a disability. A doctor may refer you to the appropriate type of doctor or specialist if your health care needs require specialized services.*

Talk with trusted family, friends, or staff

If family, friends, or staff play an important role in your health care, talk with them before the appointment about how you want and expect things to go. Tell them how you plan to advocate for yourself. If anyone will be with you during the appointment, tell them how you would like to be supported.

Create a Script or List

Health care appointments can cause anxiety and distress. It can be hard to remember everything you wanted to talk about with your doctor or make sure all your questions are answered. Considering writing out a script or list of bullet points of health care questions, concerns, or comments that you want to tell your doctor. Once at your appointment, you can refer to it as needed and make sure everything is answered before you leave the appointment.

Communication

Depending on your style of communication and comfort-level in appointments, consider having hand-gestures, eye movements, phrases/keywords, or cue cards to use to tell the doctor to slow down, repeat, or clarify what information they are telling you. This could be included in your "About Me" worksheet.

If you experience anxiety or other barriers when trying to talk with doctors, consider sending an e-mail before the appointment so that the doctor has time to read it, consider your statements, and be more prepared for your visit.

Transportation

If you rely on a transit service to get to appointments, be sure to plan ahead as able to schedule your transportation. Additionally, make sure to tell the service what kind of vehicle you need.

Resources

Great Plains ADA Center

Phone: 573-882-3600 (V/TTY)

Email: adacenter@missouri.edu

Website: www.gpadacenter.org

Disability Rights Iowa

Phone: 800-779-2502

Relay: 711

Email: info@driowa.org

Website: www.driowa.org