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Anti-Ableism Action Steps for Health Care Provision

(This list is just a starting point.

All providers need anti-ableist medical education.

This list is still evolving. It is a work in progress.)

Collaborate with disabled patients:

Disabled people are experts on their bodies, minds, and access needs. Collaboration with them, along with flexibility and creativity, will lead to better, more effective health care.

- Invite collaboration with a question such as:
“You know your body best; what do you think is going on?”
- Ask disabled people what outcomes they are seeking or what their significant concerns are.
 - Do not assume they necessarily want a cure or “big fix” for their disability.
 - Work with them to achieve their desired outcome if possible or cooperatively negotiate expectations if not.
 - Stay focused on the current medical issue. For example, when treating a wheelchair user for an ear infection, do not ask them for a medical history of their spinal cord injury.
 - No matter your curiosity, do not treat disabled people like shocking oddities.

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- Speak directly to disabled people—not to the people with them, not to the wall above their heads, not to another provider in the room.
 - If a person is non-speaking and using alternative communication devices, speak to them directly.
 - If a patient is deaf or hard-of-hearing and using an ASL interpreter, speak to them directly. If they lip read, face them when you speak. They need direct eye contact and your focus. If you're multi-tasking, communication will be much more difficult.
 - Remember speaking directly to a person does not always mean direct eye contact, which for some disabled people is very uncomfortable or impossible.
- Check-in about communication. Ask:
 - "How has communication with the office been?" "Did the intake system work for you?"
 - "Do you want to write anything down or record me while I'm talking?" "How do you want this conversation to proceed?"
 - "What will work best for you when we follow-up?" "Do you want to use the electronic messaging system?" "Would it be better to get a phone message?"

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- Be open to the knowledge and research that disabled people bring to the exam room.
 - Do not automatically discount their knowledge/research.
 - Do not assume their research means disabled people are hypochondriacs.
 - Listen to what they know about how their bodies and minds respond to various treatments and medications, including psychiatric drugs.
 - Do not trivialize their research by labeling them “internet experts.”
 - Many of disabled people are highly skilled researchers into their own medical conditions because they have to be.
- Believe disabled people’s reports of pain and actively engage with them in figuring out effective pain management strategies.
- Know your limitations. Be willing to admit what you don’t know.
- Ask for consent:
 - before you touch disabled people, particularly touch that is internal/insertive.
 - before you weigh disabled people.
 - before you bring medical students and/or other providers into the exam room to observe.
 - If you do have observers in the room, introduce them and explain why they are there. Do not create a spectacle.
 - Err on the side asking more often for consent rather than less often.

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- Listen to and abide by the answers you receive. For example, when a disabled person doesn't consent to genetic counseling, no simply means no.
- Explain procedures before doing them. Narrate them as you perform them and anticipate your actions with your words slightly so patients are not surprised or startled by what you're doing.
- Be prepared to use alternative positions for a variety of procedures. Explain what you are trying to accomplish. Disabled people know how their bodies can move and what positions they can hold; they may know a better way than you can imagine to make a particular procedure possible.
- Do not blame them if you are frustrated or impatient with their bodies. Telling them to just relax/hurry up/slow down/be still won't change anything, except to increase stress levels.
- Do not skip regular screening procedures (pap smears, mammograms, colonoscopies, etc.) because you don't have accessible equipment or because the exam will take longer. Be creative, flexible, and collaborative.
- Some low vision/blind people may wish to feel or handle equipment before it is used on them so they know more about what to expect.
 - To facilitate this, have available non-sterile duplicates of objects that must be sterile in use.

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- Ask if they would like to handle the implement so they can learn about it; don't wait to be asked.
- Help coordinate disabled people's care, rather than leaving them alone to navigate a maze of specialists.
- Recognize that making and keeping multiple medical appointments is difficult for some disabled people. Combine as much care as possible into one appointment.
- Do not withhold or gatekeep treatments, transplants, or surgeries based on a person's BMI or your assessment of their quality of life.
- Be honest and thorough about the risks and dangers of various procedures, including experimental treatments and weight-loss procedures.
- Don't make disparaging or "joking" references to adaptive equipment. Suggest and prescribe adaptive technology easily, giving disabled people options. Frame assistive devices positively, rather than as "worst case scenarios" that no one would want.
- Do not participate in involuntary medical care, including psychiatric care.
- Share all medical records easily and accessibly. Correct mistaken chart information.

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Check your assumptions:

Ableist assumptions and stereotypes inevitably impact your health care provision. You can minimize that impact by checking and changing your assumptions. Foster an understanding of how ableism is interlocked with racist, anti-poor, transphobic, homophobic, xenophobic, ageist, fatphobic, and sexist assumptions. For many disabled people, living with ableism is more difficult than dealing with their disabilities.

- Treat disabled people as human—not as objects, learning opportunities, tragedies, or problems to fix or dispose of.
- Know that medical providers are gatekeepers to resources many disabled people need for survival and therefore hold tremendous power over them.
 - Sign disabled people’s applications for accessible parking permits without grilling or hassling them.
 - Easily and quickly authorize adaptive equipment that makes the lives of disabled people more manageable.

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- Understand that many disabled people experience high levels of abuse, violence and trauma, including medical trauma and ableist medical care.
 - This trauma is deepened and made more significant by racism, poverty, transphobia, homophobia, xenophobia, and sexism.
 - Be able to tell the difference between a trauma response, defensiveness, and aggression.
 - Do not call security or the police on a person in the midst of a trauma reaction.
 - Ask disabled people all your standard screening questions about abuse, domestic violence, substance use, addictions, etc.
- Do not assume people with chronic pain are “drug seeking” or are *really* IV drug users.
 - Hone your awareness of how the assumptions about drug seeking and IV drug use particularly target and harm poor disabled people and disabled Black, Indigenous, and other people of color.
 - At the same time, do not shame, disrespect, or dehumanize people who use opioids and other criminalized and stigmatized drugs. Many IV drug users are disabled and are often self-medicating the impact of trauma, PTSD, or other disabilities.
 - Engage harm reduction, rather than gatekeeping or judgment, in prescribing pain medications.

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- Do not make assumptions about disabled people and paid work. Some of them have paid employment; others work hard but not for money. Some can't work, and still others want to work but can't find accessible jobs. Many are poor.
 - Support disabled people's applications for SSI and SSDI.
 - Check the ableist-racist assumption that disabled people can't or shouldn't work and thus deserve benefits unlike Black people who are lazy and don't deserve benefits. This assumption targets disabled Black people intensely.
 - Do not give job advice unless explicitly asked.
- Know disabled people are sexual beings and have a range of sexual orientations—lesbian, gay, bisexual, queer, asexual, heterosexual.
 - Engage with them about their sexual and reproductive health and well-being.
 - Do not make assumptions about their sexual activity, sexual orientation, partnership status, or parental status.
 - Take sexual histories, including questions about safer sex practices and STIs.
 - Do not be complicit with involuntary sterilization practices that particularly target intellectually disabled girls and women, poor women, and Black, Indigenous, and Latinx women.

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- Discuss birth control and pregnancy options with disabled people.
- Comments such as, “You’re so high functioning!” or “What do you mean, you don’t have someone to help you?” blame disabled people for not conforming to ableist stereotypes.
 - Do not project pity, tragedy, or inspiration onto disabled people’s lives.
 - At the same time, take their actual medical suffering seriously.
- Do not assume disabled people want to die.
 - Do not put DNR orders in their medical records without their consent.
 - If a person is new to disability or chronic illness, help them find new goals.
 - Be aware that legalizing physician-assisted suicide puts disabled people’s lives at risk.
- Know that many disabled people do not want to be cured or made “normal.”
- Do not assume people, even when they’re fat, want to lose weight.
- Remember that some people manifest their conditions differently than what is most typically recognized. Dig deeper. Be flexible. Think outside the box.
- Assume that if disabled and deaf people have enough access, regardless of how they communicate, they can understand and make decisions about their medical care. This includes people who use ASL, people who are non-speaking, autistic people, and intellectually disabled people.

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Create access:

Prioritizing disability access in all parts of a health care practice—from the waiting room to the exam room—is an essential part of providing good medical care. What follows is NOT an exhaustive list of access guidelines but is a good starting point.

- Be aware that medical provision with disabled people may take more time—time to communicate, time to accomplish the physical tasks of an exam, time to follow-up after an appointment.
- Make sure that your spaces (reception areas, waiting rooms, exam rooms, restrooms) and equipment (exam tables, x-ray machines, etc.) are accessible to wheelchair users and / or fat people.
- Provide chairs without arms that can support 600 pounds.
- Provide information, including HIPAA information, in multiple formats (different languages, verbal, written, plain English, web-based, videos with captions, etc.).
- Be able to provide translators and ASL interpreters as needed.
- Many deaf people strongly prefer live ASL interpreters rather than video relays.
- Provide lighting that is not fluorescent.

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- Create scent safer spaces.
 - Do not wear or use scented products (perfume, cologne, scented shampoo or lotion, etc.). Use fragrance-free soap in your soap dispensers. Do not use air fresheners, scented candles, or essential oil diffusers.
 - Do not wear clothing or use gowns or sheets that have been washed in scented laundry detergent or dried with scented fabric softeners.
- Do not assume that disabled, deaf, hard-of-hearing, and blind people in a waiting room will hear or be able to track a receptionist or nurse calling their names. Create waiting room protocols and practices that take into account a wide variety of modes of communication.
- If you can't run a test or don't have accessible equipment, say that.
 - Do not make up results.
 - Do not base diagnostic or treatment decisions on faulty results.
- If a disabled person can't fill out and/or read a form, ask them what assistance they need.
 - Make forms available via the internet and email to fill out before an appointment. Make PDFs accessible for screen readers.
 - Have a variety of adaptive writing devices available at reception.
 - Offer to scribe answers.
 - Do not shame disabled people for not being able to fill out and/or read forms.

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- Know that many disabled people need to be accompanied in medical settings by a friend, partner, and/or personal care assistant (PCA).
 - Post and verbally convey your policies about the presence of medical advocates.
 - Be clear on the differences between a PCA and a medical advocate.
 - Ask whether a person who accompanies a disabled person into an exam room is a medical advocate.
 - Tell disabled people big medical news with the same respect, privacy, and ethics that you would use with a non-disabled person.
- Check-in about access.
 - Ask disabled people about their experiences of accessibility in your office.
 - Ask about how you can create more access for them.
 - Pay close attention to their answers.
 - Use the information to improve your accessibility.