



Access to Abortion and Reproductive Health Care for People with Disabilities in a Post-*Dobbs* World

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Outline

- Disability 101
- Why is Access to Sexual and Reproductive Health Care Important for Disabled People?
- Historical Context
- Current Context
- Legal Responsibilities of Providers
 - LSC restrictions on participation in abortion litigation and proceedings
 - Reasonable accommodations and supported decision making
 - Effective communication
 - Accessible facilities and medical equipment
 - 2024 updated regulations
- Resources

Disability 101

People with Disabilities – Who Do We Mean?

- ADA and Section 504 Definition: a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.
- CRPD Definition: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”
- Disability Identity: “sense of self that includes one’s disability and feelings of connection to, or solidarity with, the disability community”

Terminology

Person First Language

- Emphasizes the person and shows that person is not defined by their disability
- Traditional rule
- Remains common, especially people with chronic illnesses and mental health or I/DD
- Examples:
 - Person with a disability
 - Person with Down Syndrome
 - Person with epilepsy

Identity First Language

- Emphasizes that disability and identity are intertwined
- Preferred in certain communities among blind, Deaf, and Autistic people
- Examples:
 - Disabled person
 - Autistic person
 - Deaf person
 - Blind person

Terminology: Disability is Not a Bad Word!

Don't say it

Handicapped

Wheelchair bound,
confined to a wheelchair

Differently abled,
handi-capable, special

Why? What to use instead?

Outdated; use disabled, person with a disability

Negative, inaccurate (wheelchair is mobility device and tool for freedom); use wheelchair user, person who uses a wheelchair

Euphemisms, condescending; use disabled, person with a disability, name of disability (person with CP, person with an intellectual disability)

Terminology: Disability is Not a Bad Word! (Continued)

<i>Don't say it</i>	<i>Why? What to use instead?</i>
Suffering from MS; HIV victim, afflicted with epilepsy	Negative, disempowering, othering; use neutral terms like person with MS, person living with HIV
Disability slurs like R-word, M-word, idiot, imbecile, moron, cripple, feeble-minded, lunatic	Offensive, rooted in eugenics and institutionalization, use current language like intellectual disability, little person, person with dwarfism
“Mind of a child”	Describe concretely impacts of intellectual or developmental disability on individual's functioning
Take care with disability nouns: avoid “the mentally ill,” “the disabled,” but know some subgroups use nouns.	

Models of Disability

Medical Model

- Disability is a medical problem that should be treated as other medical problems and cured if possible. The “problem” of disability is located squarely within the individual.
- Responsibility is placed on the individual to “overcome” their disability.

Charity Model

- People with disabilities deserve our support and care as an act of charity.
- Exception: people with stigmatized disabilities, who are viewed as causing their disabilities
- People with disabilities are seen as objects of charity.

Models of Disability (Continued)

Social Model

- The social model separates impairment, a person's bodily or functional limitation that results directly from a medical condition, from disability, which is a socially constructed disadvantage.
- This disadvantage arises from a multitude of factors including environmental, attitudinal, structural, and economic barriers.

Foundational Tenets of the Social Model

- Impairment has no negative connotation and is seen as a natural part of human diversity.
- Impairment must not be used as an excuse to deny or restrict people's rights.
- It is everybody's responsibility to remove socially constructed barriers.
- People with disabilities need rights and justice, not charity

Ableism

Definition: discrimination, prejudice, or social prejudice against people with disabilities. It manifests in various forms, from individual attitudes to systemic practices that disadvantage or discriminate against people with disabilities.

Examples

- Attitudinal Ableism:
 - Negative attitudes, stereotypes, and assumptions about the capabilities and worth of people with disabilities
 - Example: Believing that a person with a disability cannot be a good parent
- Institutional Ableism:
 - Policies, practices, and societal structures that disadvantage people with disabilities.
 - Example: Lack of medical school training on treating patients with disabilities

Accessibility vs. Reasonable Accommodations

Accessibility

“The degree to which a product, device, service, or environment is available to as many people as possible”

True accessibility occurs when a space is always, 100% of the time, welcoming to people with disabilities

Reasonable Accommodations

Adaptations made to environments, programs, policies and/or technology upon the request of an individual with a disability without imposing a disproportionate or undue burden

Accessibility is related to groups, whereas reasonable accommodations are related to individuals.

Principles of Disability Justice (Sins Invalid)

1. Intersectionality
2. Leadership of Those Most Impacted
3. Anti-Capitalist Politic
4. Cross-Movement Solidarity
5. Recognizing Wholeness (each person is full of history and life experience)
6. Sustainability
7. Commitment to cross-disability solidarity
8. Interdependence
9. Collective access (shared responsibility for access, flexibility and creativity)
10. Collective liberation (no body or mind is left behind)



Image from [Disabled and Here](#) licensed under CC

Principles of Reproductive Justice (SisterSong)

Reproductive justice is defined as the human right to:

1. Maintain personal bodily autonomy
2. Have children
3. *Not* have children
4. Parent our children in safe and sustainable communities

DJ and RJ share the themes of intersectionality, centering the most marginalized, solidarity across movements, issues, and identities, focus on access, and commitment to dismantling systems of oppression.

**Why is Access to Sexual
and Reproductive
Health Care Important
for Disabled People?**

What is Sexual and Reproductive Healthcare?

- **Sexual and reproductive health (SRH)** is a state of complete physical, mental and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce and the freedom to decide if, when, and how often to do so.
- Maintaining Sexual and Reproductive Health requires:
 - Access to accurate information about sexual and reproductive health
 - Safe, effective, affordable and acceptable contraception choices
 - Information about sexually transmitted infection prevention
 - Access to abortion
 - Once pregnant, access to skilled health care providers and services that support safety, well-being, and good outcomes

What is an Abortion?

- **Medication abortion** (also known as the abortion pill) consists of using two different medicines called mifepristone and misoprostol to end a pregnancy until 10 weeks of pregnancy. 63% of all abortions in the US are medication abortions.
- **In-clinic abortion** (also called a procedural abortion) is a medical procedure that can be done one of three ways: aspiration abortion, dilation and evacuation (D&E) and dilation and curettage (D&C).



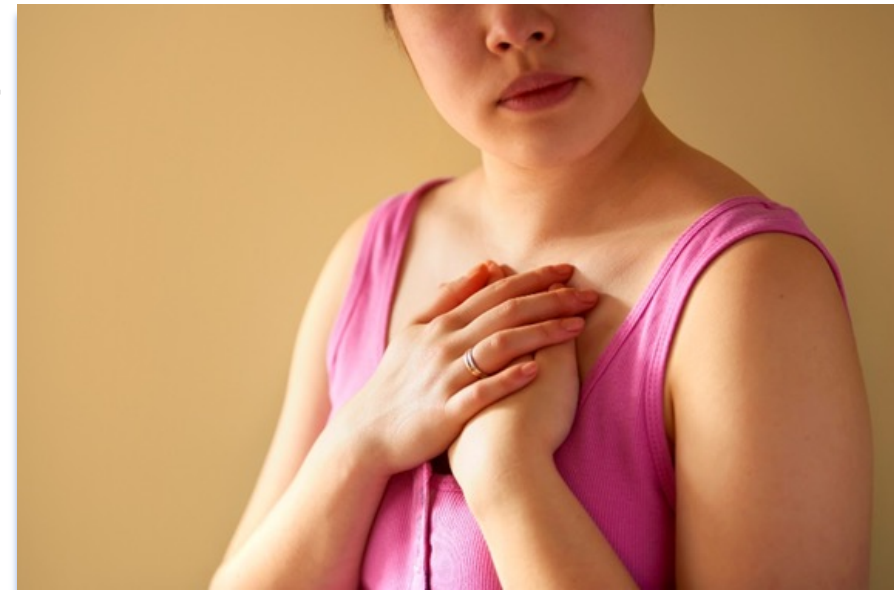
Importance of SRH Care Access for Disabled People

- People with disabilities have similar rates of sexual activity and pregnancy as non-disabled people
- Disabled people have similar fertility desires as non-disabled people
- Disabled people are less likely to receive comprehensive sexual education than non-disabled people
- Women with disabilities are significantly more likely to experience reproductive coercion or sexual violence than non-disabled people



Importance of SRH Care Access for Disabled People

- Disabled people are less likely to receive cervical cancer screening, prenatal care, and family planning services than non-disabled people
- Pregnant people with disabilities are at higher risk for nearly all adverse outcomes during pregnancy, including:
 - 6x the risk for thromboembolism;
 - Nearly 4x the risk for cardiovascular events;
 - 3x the risk for infection; and
 - 2x the risk for severe preeclampsia.
- People with disabilities are **11x more likely to die** during childbirth than non-disabled people.



Historical Context

Historical Context

Buck v. Bell (1927): the Supreme Court held that the “feeble minded” could be sterilized against their will for the “protection and health of the state.” Justice Holmes wrote “[t]hree generations of imbeciles are enough.” (Buck has never been explicitly repealed).

- After Buck, 70,000 Americans were forcibly sterilized.
- Women of color were more likely to be involuntarily sterilized than white women.
- 31 states and Washington DC still have laws on the books that allow forced sterilizations.



Arthur Estabrook Papers, M.E.
Grenander Special Collections &
Archives, University at Albany, SUNY.

Historical Context (Continued)

- Other eugenic policies adopted in the U.S. during the 20th Century include:
 - Forced institutionalization and segregation
 - Limitations on the ability of people with disabilities to get married and have sex before the age of 45
- History of abortion access advocacy and discussions of disability
 - 1960s-70s - Disability based justifications to support access to abortion
 - Now - Reason bans to prevent access to abortion
 - Neither of these support bodily autonomy for disabled people!

Current Context

Supreme Court Cases Affecting the Legal Landscape of Abortion Access

- *Dobbs v. Jackson Women's Health Org.* (2022)
 - Stripped Americans of their federal constitutional right to an abortion
 - Currently, 3 million women with disabilities live in states that have banned or are likely to ban abortion
- *FDA v. Alliance for Hippocratic Medicine* (2024)
 - AHM, an anti-abortion group challenging the FDA's decision to remove unnecessary restrictions on access to the abortion medication, mifepristone
 - On June 13th, the Court dismissed the case on standing, meaning that current access to medication abortion remains unchanged but new parties could challenge mifepristone in the future
- *Moyle v. United States* (2024)
 - Legal issue is whether a federal law called EMTALA preempts (overrides) state abortion bans
 - The Court dismissed the case for being “improvidently granted” and sent it back to the lower courts to decide the issue on the merits.

Socio-Economic Barriers

- 2x more likely to live below the federal poverty line
- 3x more likely to be unemployed
- 1 in 10 lack health insurance
- Racial disparities:
 - Black people with disabilities are almost 55% more likely to live below the poverty line compared to white people with disabilities
 - 50% higher unemployment among Black and Latino people with disabilities compared to white people with disabilities

Travel Barriers

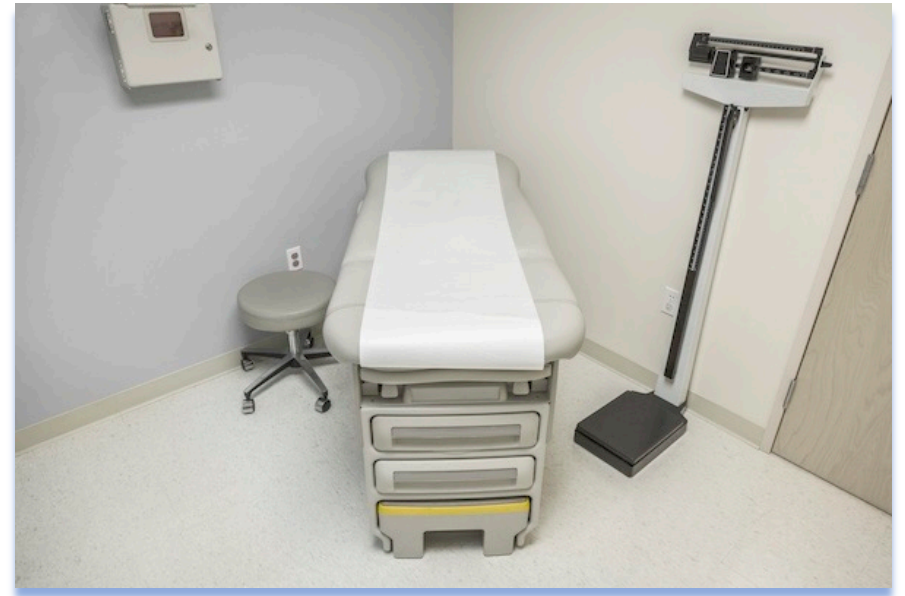
- 3M disabled women of reproductive age (52.3%) live in the 26 states that banned or are likely to ban abortion since *Dobbs*.
- Transportation barriers
 - Reliance on others for transportation
 - Inaccessible public transit/insufficient paratransit services
 - Inaccessible ride-share services
 - Inaccessible (and expensive) air travel
- Barriers result in less access to care
 - People with disabilities are more likely to report experiencing logistical barriers like arranging transportation to a reproductive care appointment than non-disabled people (50.7% vs. 29.7%).

Health Systems Barriers

- Disabled people often excluded from health disparities research
 - Designated as health disparities population in 2023
- ADA compliance enforcement is lacking
- Federal insurance (Medicare/Medicaid)
 - 900,000 disabled reproductive aged women rely on Medicare.
 - Medicare Part B generally does not cover contraception for the sole purpose of preventing pregnancy. Most Part D enrollees are in plans that cover contraceptive pills, rings, patches, and injections, but not IUDs or implants.
 - Hyde amendment: prohibits the use of federal funds in the provision of abortion care unless the life of the mother is in danger or the pregnancy is the result of rape or incest

Barriers in the Clinic

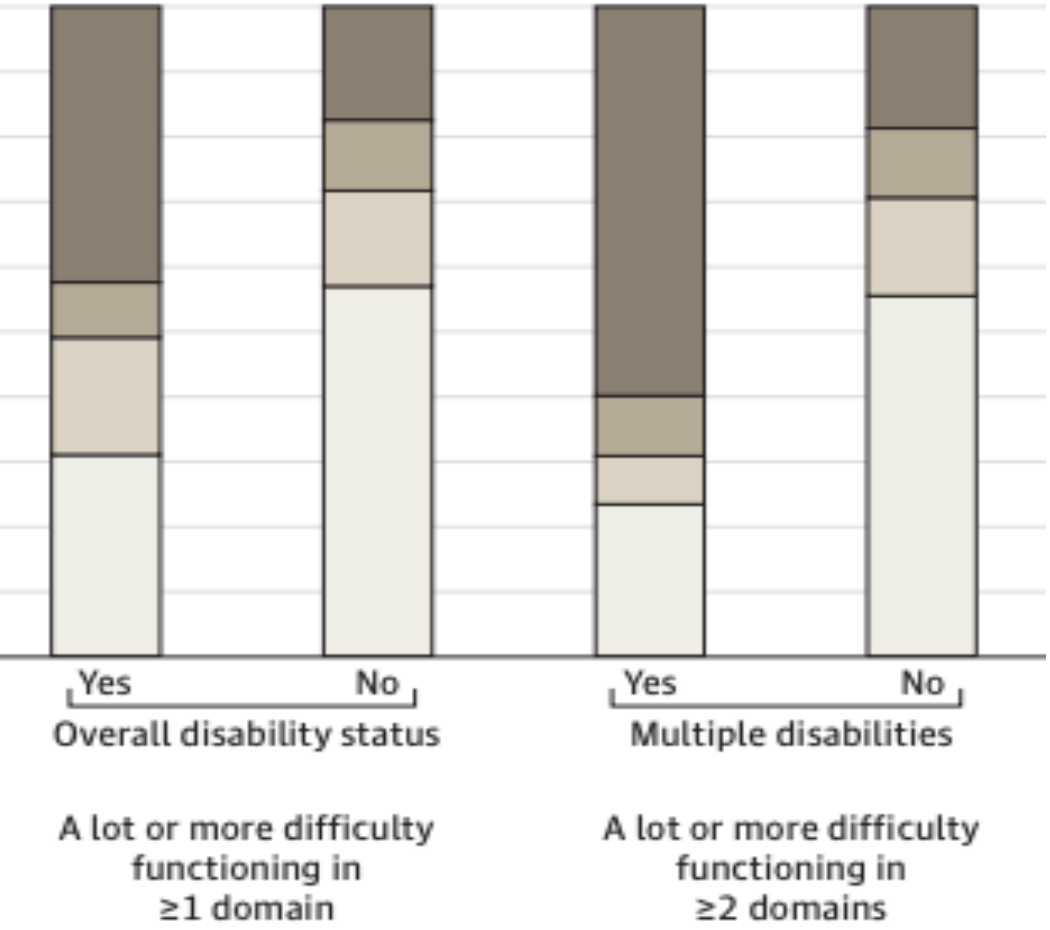
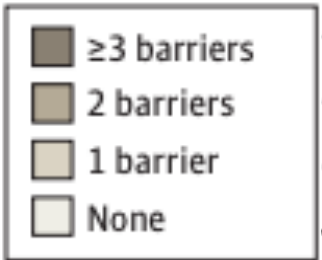
- Inaccessible facilities
- Lack of accessible medical equipment
- Lack of provider and staff knowledge
 - Legal obligations
 - Training on caring for disabled patients
- Provider and staff biases and assumptions, medical mistreatment



Barriers Compound & Limit Overall Care Access

Number of Barriers to Reproductive Health Services in the Past 3 Years by Disability Indicators

- Types of Barriers**
- Logistical
 - Access
 - Cost
 - Privacy
 - Interpersonal Relationship



M. Antonia Biggs et al., *Access to Reproductive Health Services Among People with Disabilities*, JAMA Network Open (Nov. 29, 2023)

Legal Responsibilities of Healthcare Providers

Note: Legal Services Corporation (LSC) Restrictions

- Organizations funded by the LSC may not:
 - "provide legal assistance with respect to any **proceeding or litigation** which seeks to **procure a nontherapeutic abortion** or to compel any individual or institution to perform an abortion, or assist in the performance of an abortion, or provide facilities for the performance of an abortion, contrary to the religious beliefs or moral convictions of such individual or institution[.]" 42 U.S.C. § 2996f(b)(8).
 - Covered in LSC Program Letter 22-2
- There are no special LSC restrictions on public education, training, or legal information concerning access to reproductive and sexual health services, including abortion.
- LSC-funded organizations may also engage in any proceedings and litigation representing or advocating for clients seeking other types of reproductive and sexual health services (not abortion).

Disability Rights Laws

- **Americans with Disabilities Act ("ADA")**: federal civil rights law that prohibits discrimination on the basis of disability in everyday activities
 - Privately owned entities are covered by Title III as "places of public accommodation"
 - Publicly owned and operated entities are covered by Title II as "public entities"
- **Section 504 of the Rehabilitation Act of 1973 ("Section 504")**: federal law that prohibits discrimination on the basis of disability by employers and organizations that receive federal financial assistance
- **Section 1557 of the Affordable Care Act ("Section 1557")**: federal law that prohibits discrimination on the basis of race, color, national origin, age, **disability**, or sex in health programs or activities that receive federal financial assistance

Clinics' Responsibilities

The ADA, Section 1557, and Section 504 prohibit discrimination against people with disabilities and require medical providers to make their services and programs available in an accessible manner. This includes:

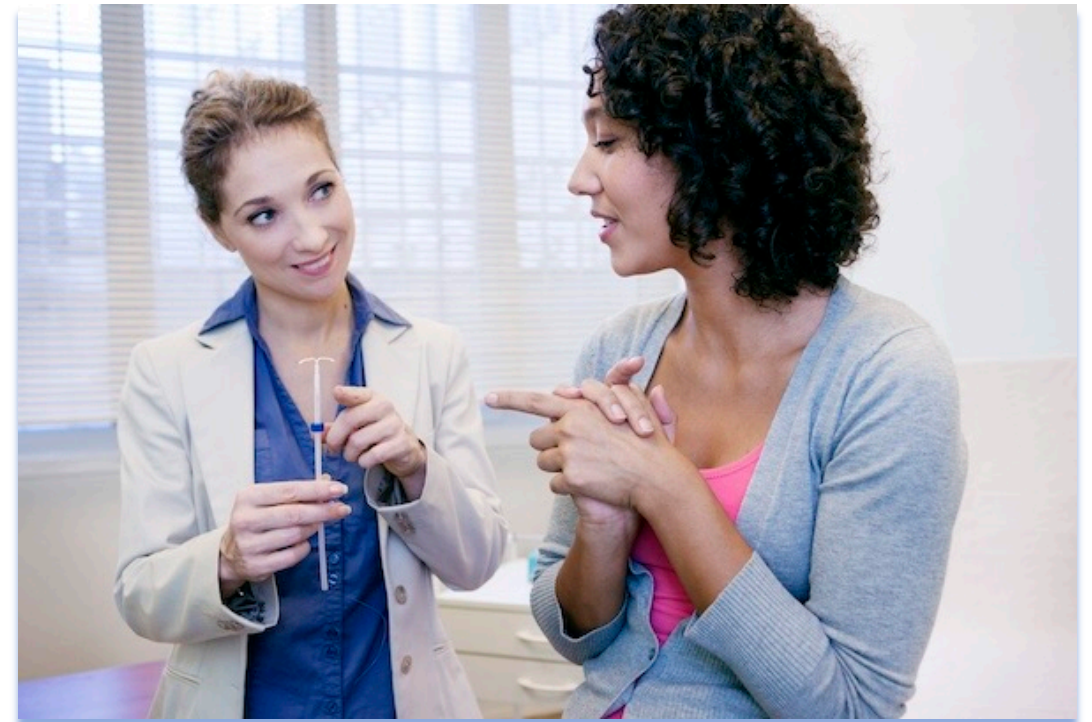
- Providing reasonable accommodations (RAs)
- Ensuring effective communication
- Having accessible facilities and equipment



Reasonable Accommodations (RAs)

Definition: Changes to the usual way of doing things to include people with disabilities and provide equal opportunity for them to benefit from services.

It is discrimination to fail to provide reasonable accommodations to disabled patients unless doing so will “fundamentally alter” the nature of the services or benefits provided or result in an “undue burden.”



Examples of Common RAs

- Reserving additional time for an appointment
 - Allow for physical transferring, engaging with interpreters, checking understanding
- Allowing a support person to be present at an appointment
- Utilizing supported decision-making
- Performing a pelvic exam in an alternative position
- Moving items that might block the path of travel
- Reserving an appointment room that has accessible equipment
- Allowing time for breaks
- Turning down the brightness of the exam room lights
- Providing a written outline of the information discussed
- Wearing a mask if a patient requests one
- **The possibilities are endless!**

RA Spotlight: Supported Decision-Making

- Supported decision-making ("SDM"): individualized arrangement in which a disabled adult chooses one or more people they trust as supporters to help them understand, communicate, make, or act on their own choices.
- Looks different for each person
- Can be formal (written) or informal agreement
- Can strengthen capacity and avoid the need for a conservator in decision-making
- Recognized under California law, see Probate Code §§ 1800(e), 1800.3(c), 1821(a)(1)(C)(i), 1836(b)(1), (d)(3), (4), 2113, Cal. Welf. & Ins. Code § 21000 to 21008

Supported Decision-Making v. Conservatorship

SDM

- Disabled person makes their own choices but receives help from supporters in the process
- Disabled person chooses their own supporters
- Can strengthen capacity and avoid need for conservatorship

Conservatorship

- Conservator makes choices for the person with a disability, often without consulting them.
- Conservator is appointed by a court and can only be removed by a court
- Conservator's decisions must be approved by a court

Capacity

- Capacity is spectrum – not yes/no question
 - Changes with context, topic, emotional & physical state, etc.
 - Individual may have capacity to make medical or mental health decisions without understanding every aspect of diagnosis or treatment
- Capacity is flexible and can be strengthened
 - Plain language can strengthen capacity
 - Reasonable accommodations can strengthen capacity: time of day; format, duration, location of meetings; breaks; repetition
 - Supported decision-making (SDM) can strengthen capacity
 - Assess capacity with preferred supports in place

Who Can Benefit From SDM?

- Anyone! Everyone asks others for support when making important decisions.
- SDM may be especially helpful for people who need additional help with:
 - Identifying and weighing options
 - Understanding the risks and benefits
 - Choosing between options
 - Communicating the choice
 - Acting on the choice
- A person who has a guardian in a different part of their life (for example, their finances) may still be competent to make decisions about their medical care with or without support.



Effective Communication

- Under the ADA, Section 504, and Section 1557 medical providers are required to ensure effective communication with disabled patients. This may include the provision of auxiliary aids and services.
- Ensuring effective communication may require:
 - Qualified interpreters (in-person or through video remote interpreting (VRI));
 - Real-time captioning, particularly for video telemedicine;
 - Assistive listening devices and systems (e.g. hearing loop, pocket talker);
 - Offering written materials in alternative formats such as Braille materials or large print;
 - Providing written notes summarizing the information provided; and
 - Using plain language (e.g. sixth grade English) and visual aids

Accessible Facilities and Medical Equipment

- The ADA and Section 504 require that medical providers give disabled people full and equal access to their facilities and medical equipment.
 - Government providers that receive federal money must make their programs **as a whole** accessible to and usable by individuals with disabilities.
- Nondiscrimination includes:
 - Removing architectural barriers
 - Acquiring accessible medical equipment - now **required** under new Section 504 regulations
 - Where barrier removal would be an undue burden, making services available through an alternative location or method

New Section 504 Regulations

- On May 9, 2024, HHS released their finalized rule for Section 504 regulations which goes into effect on **July 8, 2024**:
- Prohibits provision, denials or limitations of medical treatment when based on:
 - Bias or stereotypes about an individual's disability;
 - Judgments that they will be a burden on others due to their disability, including, but not limited to caregivers, family, or society; or
 - A belief that the life of a person with a disability has lesser value than a person without a disability, or that life with a disability is not worth living.
- Prohibits discrimination in child welfare, including decisions based on stereotypes or generalizations about a child with a disability; or that a parent or caregiver with a disability cannot safely care for a child.
- Web, kiosk, and mobile accessibility is required
- Incorporates the U.S. Access Board's 2017 Standards for Accessible Medical Diagnostic Equipment (MDE)
- 45 CFR § 84

New Section 1557 Regulations

- On April 26, HHS released their finalized rule for Nondiscrimination in Health Programs and Activities which goes into effect **July 5, 2024**:
- Requires covered health care providers, insurers, grantees, and others to let people know that language assistance and accessibility services are available to patients at no cost. Covered entities are also required to train their staff on these policies and procedures.
- Clarifies that covered health programs and activities offered via telehealth must also be accessible to individuals with limited English proficiency and individuals with disabilities.
- Protects against discrimination by codifying that Section 1557's prohibition against discrimination based on sex includes LGBTQI+ patients.
- 42 CFR Parts 438, 440, 457, 460; 45 CFR Parts 80, 84, 92, 147, 155, 156

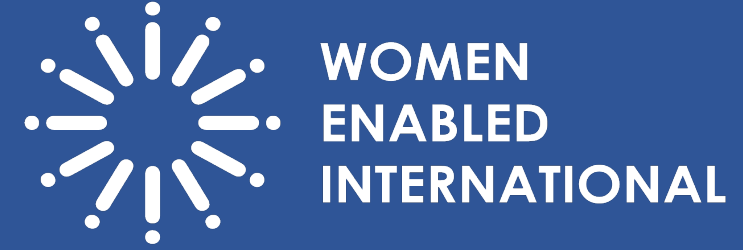
New HIPAA Regulations

- On April 22, HHS released the finalized rule for HIPAA Privacy Rule To Support Reproductive Health Care Privacy which went into effect on **June 25, 2024**:
- Prohibits the use or disclosure of protected health information (PHI) by a covered health care provider, health plan, or health care clearinghouse—or their business associate—for either of the following activities:
 - To conduct a criminal, civil, or administrative investigation into or impose criminal, civil, or administrative liability on any person for the mere act of seeking, obtaining, providing, or facilitating reproductive health care, where such health care is lawful under the circumstances in which it is provided.
 - The identification of any person for the purpose of conducting such investigation or imposing such liability
- Creates a presumption that the reproductive health care provided by a person other than the covered entity receiving the request was lawful.
- 42 CFR § 2

Resources

- **National Network of Abortion Funds** is a directory of abortion funds and other support resources in the US.
- **Abortion Finder** is a comprehensive directory of trusted (and verified) abortion service providers and assistance resources in the US.
- **I Need an A** is a comprehensive resource guide for abortion seekers in the US.
- **All Options Talkline** is a free peer counseling support network for anyone at any stage in or after their pregnancy. They can be reached at (888) 493-0092.
- **Exhale Pro-Voice** is a free talkline for people who need emotional support after having an abortion. They can be reached at (866) 439-4253.
- **If/When/How Repro Legal Helpline** provides free, confidential legal services for your reproductive life, including abortion, pregnancy loss, and birth. They can be reached at (844) 868-2812 or at <https://www.reprolegalhelpline.org/>

Questions?



Thank You!

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