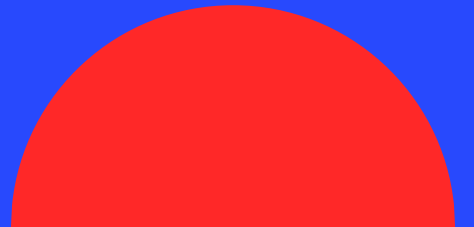
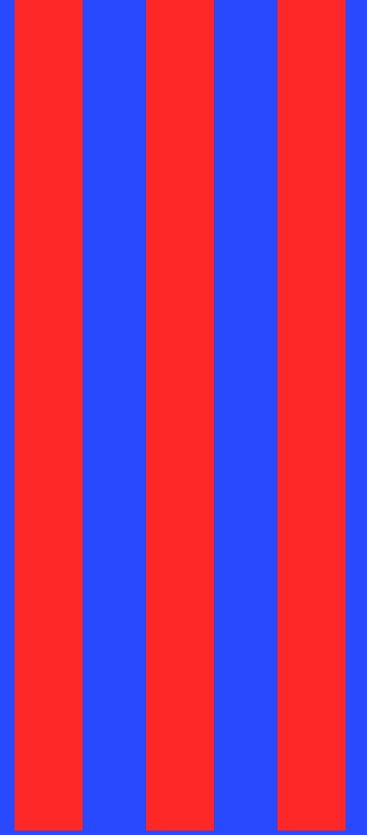
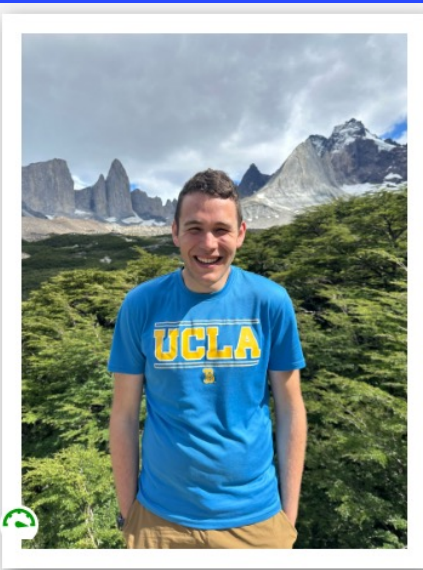


# **Short Takes** on disability and sexual and reproductive health





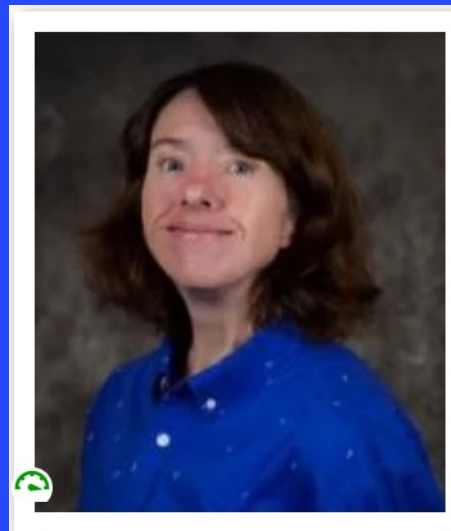
Lauren Clark



Adam Kipust



Kate Schaller,  
Instructional Designer



Kecia Weller



Annemarie Lawrence

**UCLA**

**Disability Studies**

**UCLA**

Semel Institute  
**Tarjan Center**

This course was funded, in part, by a grant from US DHHS-ACL *Expanding the Public Health Workforce*

# Agenda

Overview of the course

Student short takes on disability and sexual  
and reproductive health

Wrap up and Q&A



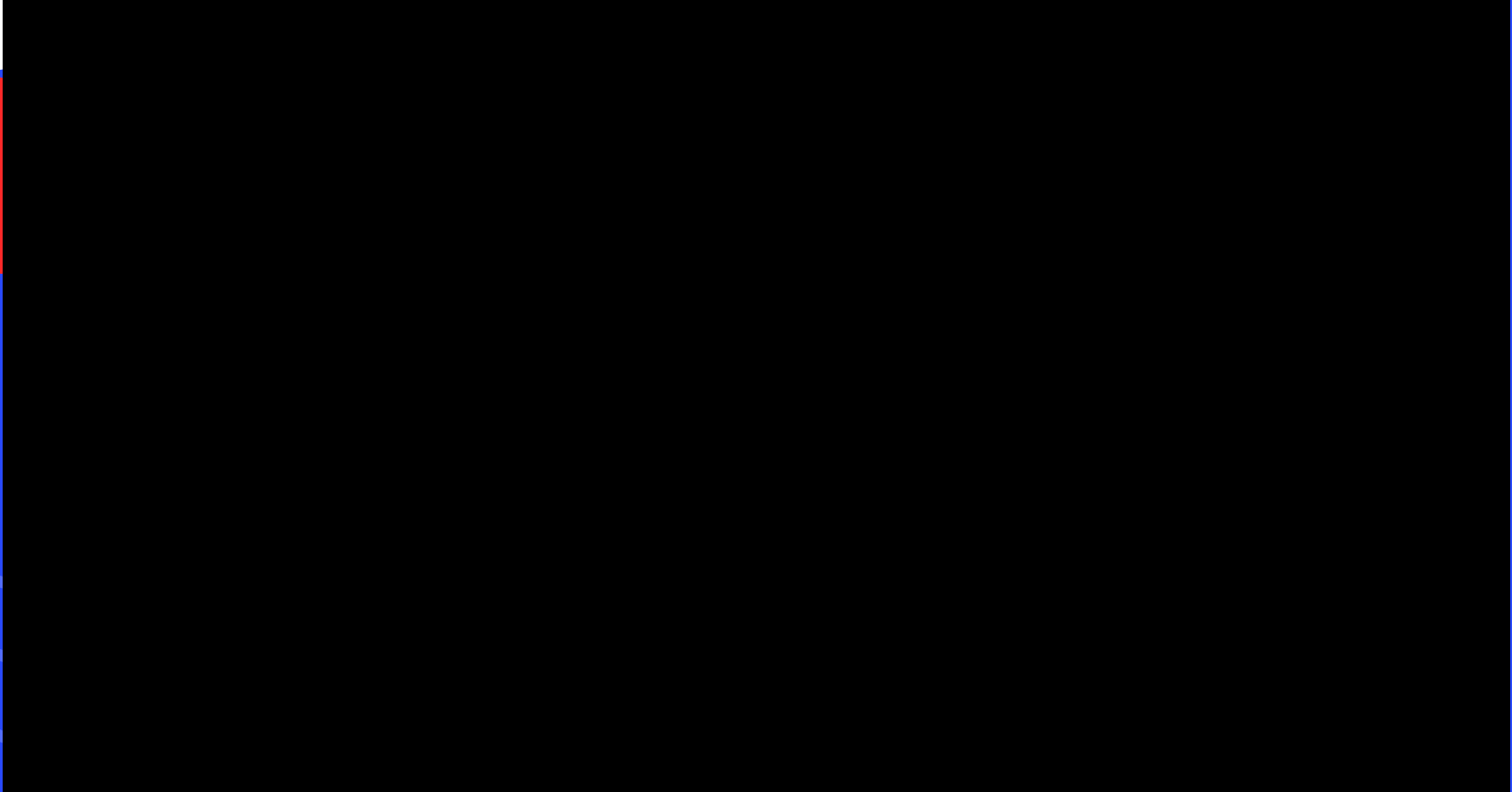


# Sexual and Reproductive Health Care for People with Disabilities



## Overview of the Course



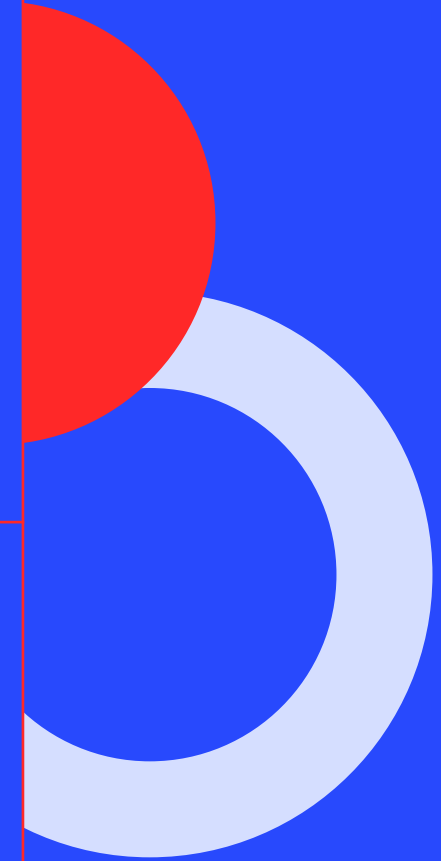


Unfolding Case Study

# Defining Sexual and Reproductive Health



Sexual health	<ul style="list-style-type: none"><li>• positive and respectful approach to sexuality and relationships</li><li>• possibility of having pleasurable and safe sexual experiences</li><li>• without coercion, discrimination, or violence</li></ul>
Reproductive justice	<ul style="list-style-type: none"><li>• the right to have children</li><li>• the right to not have children</li><li>• the right to nurture the children you have in a safe and healthy environment</li></ul>
Disability justice	<ul style="list-style-type: none"><li>• cross-disability framework</li><li>• values access, intersectionality, leadership of the most impacted, and wholeness</li></ul>





# Short Takes

## disability and sexual & reproductive health

Topic	Students
Sex Education	Hannah Bowes & Marisol Mercado
Accessibility of health services	Joslynn Cruz & Eli Whitaker
Contraception	Isaac Guevara & Silence Jackson
Sexual Violence	Evelyn Canales
Prenatal screening and testing for aneuploidy	Lucia Gideon & Robin Sunada
Right to parent	Alexis Herrera & Delanie Renteria

# Sex Education

Hannah Bowes & Marisol Mercado



# Sexual Education For People With Disabilities







# Sexual Education

An education program that is easy to understand and encourages natural, healthy sexuality. This program includes education on infections that pass from person to person, birth control, healthy relationships, and anatomy.



# Sexual Education Statistics

18

Out of 50  
States

Require that the  
program content is  
medically accurate or  
evidence-based

6

Out of 50  
States

Offer **optional** extra  
materials to help  
people with disabilities  
learn

3

Out of 50  
States

Clearly include  
people with disabilities  
in their sex education  
requirements



# Importance of Sexual Education



## Autonomy

Access to education and resources is a basic right for everyone. It's important for both reproductive rights and for people with disabilities. When people have access, they can learn how to control their own sexual experiences.

## Consent

Evidence shows that inclusive sex ed programs can reduce relationship violence by about 60%





# Concerns For People With Disabilities



A

Ableism



People with disabilities are often not seen as sexual beings with natural human desire

B

Guardianship



Guardians can stop students from receiving sexual education and block privacy with health providers

C

Vulnerability



Being left out of sex education makes people with disabilities more vulnerable to sexual assault and being used

# Improvements To Make



## Trust

Educators must build trust with the disability community

## Inclusivity

Curriculum should be easy to understand for all

## Access

Sex education should part of special education

## Policy

Officials must protect access to sex education for people with disabilities



# References



Alexander A. Boni-Saenz. "Discussing and Assessing Capacity for Sexual Consent,"  
Psychiatric Times, July 29, 2016,  
<https://www.psychiatrictimes.com/view/discussing-and-assessing-capacity-sexual-consent>

Future of Sex Education Initiative. National Sex Education Standards: Core Content and  
Skills, K–12, [http://  
www.advocatesforyouth.org/wp-content/uploads/2020/03/NSES-2020-web.pdf](http://www.advocatesforyouth.org/wp-content/uploads/2020/03/NSES-2020-web.pdf)

> National Partnership for Women & Families and Autistic Self Advocacy Network. Access,  
Autonomy, and Dignity: Comprehensive Sexuality Education for People With Disabilities.  
Sept. 2021,  
[nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-sexed.pdf](https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-sexed.pdf).





# Questions about sex education and people with disabilities?



# Accessibility of health services

Joslynn Cruz & Eli Whitaker





# Accessibility of Health Care for People With Disabilities

Eli Whitaker and Joslynn Cruz



01

## What Guarantees Accessibility?

Combination of legal frameworks and policies along with funding

02

## How accessible is healthcare now?

The Americans with Disabilities Act of 1990

03

## Potential Practice and Policy Intervention

Create education awareness campaigns that promote healthcare access





# 01

## What guarantees accessible health care?

### Ensures:



- Public services provide inclusive architecture to people with disabilities



- Modifications are made by public services to allow and accommodate people with disabilities

### Prohibits:



- Refusal of service towards those with a disability solely on the grounds of the disability itself



- Providing a different, or lower level, of service and benefits to people with disabilities

The Americans with Disabilities Act of 1990  
*(This civil rights law is the foundation of all discrimination rights in the US.)*





# How accessible is healthcare now?

*"I think you need a lot more care, and I am not the doctor for you."*

## Barriers from the Provider Side:

- Relying on caregivers  
*Example: a provider does not offer an ASL interpreter and will instead ask the caregiver for the information instead of the patient*
- Inadequate expertise  
*Example: providers may not be properly trained on how to physical transfer patients with a disability without harming themselves or the patient*
- Discriminatory attitude  
*Example: providers may find accommodating a disability burdensome, denying service rather than working towards a solution*
- ADA Knowledge  
*Example: the ADA is not a mandatory consideration for medical providers, many may not know the legal expectations to uphold*

*"they can create a big thing out of nothing."*





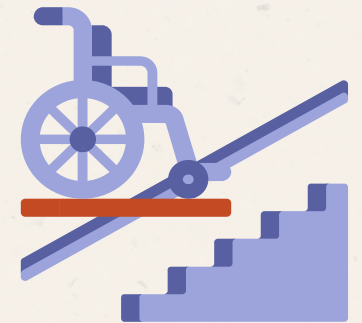
# How accessible is healthcare now?

*"They have basically said like if you want to use a lift, you need to find somebody else."*

## Barriers from the Patient Side:

- Unaccommodating architecture  
*Example: a doorway is too narrow for an individual to bring their wheelchair through*
- Inadequate medical equipment  
*Example: a medical bench does not have adjustable height for somebody with low mobility*
- Lack of social consideration  
*Example: patronizing or treating somebody with a disability like a child*
- Inconsiderate aids  
*Example: an interpreter loudly asking private medical questions in the lobby*

*"I can't really lay down anymore without having breathing equipment, so I have to bring that in, plug that in, set it up. I just dread the next time I have to do it."*





# 03

## Potential Practice and Policy Intervention

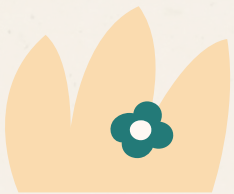


- Solving the gap in treatment between able bodied people and people with disabilities which is created from ignorance and misinformation.
- Increasing access and availability of medical equipment along with funding
- Advocacy towards reforming the guardianship policies of reproductive health amongst people with disabilities
- Being self aware as an able bodied person especially in the medical field

What dictates someone who is able bodied and someone who is not?

“the 1927 *Buck v. Bell* decision, the U.S. Supreme Court upheld the forced sterilization of disabled people and people with “perceived” disabilities”

**MY BODY.  
MY CHOICE.**



# References

## Health Affairs Article:

Blumenthal, David, et al. "Health Care in 2022: The Year in Review." Health Affairs, vol. 41, no. 12, 2022, <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00475>.

## JOGNN Article:

Harris, Rebecca E., et al. "Nursing Practice and Maternal Health." Journal of Obstetric, Gynecologic & Neonatal Nursing, vol. 50, no. 5, 2021, [https://www.jognn.org/article/S0884-2175\(21\)00126-X/fulltext](https://www.jognn.org/article/S0884-2175(21)00126-X/fulltext).

## Senate Bill 933:

"S.933 - Americans with Disabilities Act of 1990." Congress.gov, 101st Congress, 1990, <https://www.congress.gov/bill/101st-congress/senate-bill/933>.



**Questions about  
accessibility of  
sexual and  
reproductive health  
services and people  
with disabilities?**





# Contraception

Isaac Guevara & Silence Jackson





# Contraception







# What are contraceptives?

Contraceptives (aka birth control) include drugs, devices, and surgeries that prevent pregnancy. Also these methods help promote freedom and ease the pains and flow of heavy menstruation which allows more independence.

# Meet Claire

- 30 year old female
- Has an intellectual disability
- Affects her ability to travel and remember
- She does not want kids soon and is interested in using contraceptives.





# Contraceptive Access for Women with Disabilities

- Planned Parenthood and clinics have made access to contraceptives easier for people who ask for them.
- Though there have been many moves to make these tools accessible to all, there remain to be issues.
  - Independence
  - Transportation
  - Ableism





# Disability Access

## Independence

Guardians or caretakers can prevent access to contraceptives. There can be many reasons but usually this is because they don't want them to be sexually active

## Transportation

People with disabilities may have a hard time navigating driving and even public transport. This stops them from going to Planned Parenthood, hospitals, or clinics.

## Ableism

Doctors, nurses, and guardians can have ableism. This can lead to intentional barriers and/or not offering contraceptives to people with disability variations.





# Administered Contraceptive Types



IUD:  
99% Effective  
Lasts Up to 3-12  
years  
You need a doctor  
One time visit



Implant:  
99% effective  
Lasts Up to 5 years  
You need a doctor!  
One time visit



Birth Control Shot:  
96% effective  
You need a doctor  
A visit every 3  
months





# Self-Use Contraceptive Types



Birth Control Patch  
93% effective  
No Doctor Needed  
Change patch every  
week



Birth Control Pill  
93% effective  
No Doctor Needed  
One pill every day



Condoms  
87% effective  
No Doctor Needed  
Use before sexual  
activity



# What Should Claire Use? The IUD!

- Based on what we know, Claire's disability affects her ability to travel to places and keeping track of time.
- So the contraceptive she should use, should not be a constant doctor visit and should not need a schedule to remember.
- The IUD lasts 3 to 12 years and only needs one visit that can be planned to her needs. She doesn't need to worry about reapplication. It perfectly suits her needs!





## In summary



- Contraception in order to prevent pregnancy and ease menstruation have expanded but transportation, ableism, and guardians can be barriers.
- Claire with advice was able to choose the IUD as the best option for her to work around her disability while taking a contraceptive.
- Various methods of contraception exist but with advice finding the right one is easy. Even if its assisted or not.



# Key References

- Reproductive Justice for Disabled Women: Ending Systemic Discrimination  
<https://www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination/>
- Rethinking Guardianship To Protect Disabled People's Reproductive Rights  
<https://www.americanprogress.org/article/rethinking-guardianship-to-protect-disabled-peoples-reproductive-rights/>
- Birth Control <https://www.plannedparenthood.org/learn/birth-control>



# Questions about contraception for people with disabilities?



# Sexual Violence

Evelyn Canales





# Sexual Violence Against People With Disabilities

Evelyn Canales





**1**

## **Podcast Highlight**

NPR's Report of Sexual Assault on People with Intellectual Disabilities

**2**

## **Understanding the Concern**

Key Facts: Sexual Violence and Disabilities

**3**

## **Towards Solutions**

Addressing Sexual Violence - Practices and Policies

# Content Notice

This presentation will discuss topics related to sexual violence and sexual assault, which may be upsetting for some individuals.





An illustration of a person with dark skin and short black hair, wearing a light blue V-neck shirt and teal pants, sitting in a black wheelchair. They are positioned on the left side of the frame, looking towards the right. The wheelchair has large black wheels and a smaller front wheel. The person's feet are on black footrests. The background is a light beige color with a subtle pattern of small grey dots. In the bottom right corner, there are stylized blue and green plants.

1

# Podcast Highlight

“Abused and Betrayed” - This NPR podcast looks into sexual assault in the disability community.

## In Their Own Words: People With Intellectual Disabilities Talk About Rape

January 20, 2018 • In the final piece of NPR's series on the sexual assault epidemic against people with intellectual disabilities, we hear from victims themselves about how these experiences shape their lives.

▶ LISTEN · 7:49

+ PLAYLIST



Lizzie Chen for NPR; Claire Harbage and Meg Anderson/NPR



**NPR - Abused and Betrayed**



# Common Sexual Victimization Experiences



## Perceptions and Stereotypes

Harmful misconceptions contribute to sexual violence against disabled people.

“People look at people with disability as, a lot of time, they look at us thinking that we don’t know no better. Because a lot of us is quiet and easygoing, they think that we weakling. And we not.” -Thelma Green

“It happens to people like us, and why is because we’re easy targets to take advantage of.” -Cindy Whitaker







# Common Sexual Victimization Experiences



## Targeting

Often, the people who hurt disabled people are those meant to help them.

“Yes, it’s happened to me. It was a staff person. It started out where he was buying pop for me and candy for me, ... Then one time he asked me to come down in the basement. He wanted to show me something. And I trusted him. That’s where that happened.” -Sam Maxwell



# Common Sexual Victimization Experiences



## Pain and Awareness

Disabled survivors of sexual violence feel physical and emotional pain.

“I can remember everything. Even though I have a disability, I still remember it.” -Kathleen

“We do feel pain all the time. They’re ignorant that they don’t see that. They don’t want to see it. They close their eyes to it, close their mind to it.” -Carolyn Morgan







# Common Sexual Victimization Experiences



## **Fear and Silence**

Reporting is hard due to stigma, disbelief, and victimization.

“Some with disabilities are afraid to report it, because they’re afraid it will make them look bad, worse than they already are, because people already look down on you, because you’re disabled. It felt like the world was against me.” -Whitaker

“They think if you got a disability that means you lie, that you can’t really tell the truth or you don’t know what the truth is.” - Mangrum

“We are not believed. Right away, the cops think that you asked for it. So, you really do have keep tellin’. They don’t even think that we’re reliable witnesses.” -Robinson





# 2

## Understanding the Concern

Statistics and Key Points - The hidden epidemic of sexual violence against people with disabilities.



# U.S. Statistics about Sexual Violence and Disability

In the United States in 2009, the Department of Justice found that people with disabilities were the victims of approximately:

**47,000**

Rapes

**90%**

More than 90 percent of people with disabilities will experience sexual abuse in their lifetime, no matter their gender.

**3x**

Women and girls with disabilities are three times more likely to be victims compared to those without disabilities.

**3%**

Only 3 percent of sexual abuse cases involving people with developmental disabilities are ever reported.





# Why is this number so low?

- Lack of or limited sex education
  - Difficulty recognizing abuse
  - Decreased awareness of available support services
- Fear...
  - Of losing the care needed for independent living
  - Of not being believed
- Inaccessible and/or inadequate support services
  - Buildings might not be easy to enter
  - Untrained and unprepared service providers
  - Lack of proper plans in place





# Sexual Violence and Disability in the Courtroom



The sexual assault of someone with a disability is one of the easiest crimes to get away with.

## Glen Ridge Rape Case


- The first time a woman with an intellectual disability was sexually assaulted and it got national attention.
- Four of the young men were convicted.

## Statistics Then (1994):

- Even when an offender was found, only 24% were charged with a crime.
- Of those charged, only 8% percent were convicted.

## Statistics Now (2012-2015):

State data:

- Texas - less than 1% of sexual assault allegations were confirmed.
  - Florida - about 5% were proven true
  - Ohio - about 23% were proven true
  - Pennsylvania - 34% of claims were confirmed but only 40% of those were reported to the police
- 

# Why are these numbers so low?

- People with intellectual disabilities may:
  - have trouble speaking
  - have trouble telling specific details
  - be easy to confuse in a courtroom
- These cases require a lot of extra work and effort
  - Victims need to understand the legal process
  - Victims need to become comfortable in a courtroom
    - Service Animals
    - Videotape Testimony







# 3

## Towards Solutions

Strategies and Interventions



# Possible Solutions

## Education and Training

- Teach people with disabilities about sexual harassment and assault.
- Show them how to recognize when something wrong is happening and what to do if they need help.

## Accessible Reporting Mechanisms

- Make it easy for people with disabilities to report sexual violence.
- Make reporting systems private and easy to understand.
- Provide specialized training to responders.

## Support Services

- Expand access to support services, such as counseling, medical assistance, and legal help.
  - Build relationships between different organizations
- Make services easily accessible and easy to understand.
  - Safe and supportive environments
  - Ensure that programs follow disability laws
- Assign trained staff to assist survivors with disabilities.
  - Ensure that they are available for support
  - Develop clear plans for assistance
- Involve survivors in the design of these services.
  - Ensure that their needs are met
  - Feedback and improvement





# “Wynona’s House”



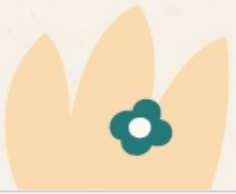
Waiting Room



Examination Room



Dolls and Sketches -  
to help describe an  
abuse





# Summary

- Sexual violence against people with disabilities is a significant concern
- Key points include higher rates of abuse among women and girls with disabilities, underreporting cases, and barriers to reporting
- Perpetrators are often individuals within the victim's support system
- Interventions include:
  - Sexual assault prevention training for people with disabilities
  - Better reporting systems when assault happens
  - More access to support services for victims





# Resources

- “Prevalence of Violence Committed against Persons with Disabilities.” *Mass.Gov*, [www.mass.gov/info-details/prevalence-of-violence-committed-against-persons-with-disabilities](https://www.mass.gov/info-details/prevalence-of-violence-committed-against-persons-with-disabilities). Accessed 15 May 2024.
- Received by Lauren Clark, *Preventing and Addressing Sexual Violence Against People with I/DD*, 30 Apr. 2024.
- Shapiro, Joseph. “In Their Own Words: People with Intellectual Disabilities Talk about Rape.” *NPR*, NPR, 20 Jan. 2018, [www.npr.org/2018/01/20/577064075/in-their-own-words-people-with-intellectual-disabilities-talk-about-rape](https://www.npr.org/2018/01/20/577064075/in-their-own-words-people-with-intellectual-disabilities-talk-about-rape).
- Thompson, Vilissa, and Mia Ives-Rublee. “Reproductive Justice for Disabled Women: Ending Systemic Discrimination.” *Center for American Progress*, 13 Apr. 2022, [www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination/](https://www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination/).



# Questions about sexual violence and people with disabilities?

Questions?



# Prenatal screening and testing for aneuploidy

Lucia Gideon & Robin Sunada





# Prenatal Screening and Testing for Aneuploidy

Robin Sunada and Lucia Gideon

# What??

- ❖ Prenatal screening : a medical test that tells you if your baby is more/less likely to have genetic differences.
- ❖ An expecting mother will go in to a pregnancy clinic or general medical office and have this process performed by a healthcare professional.
- ❖ Prenatal testing : the genetic sample is sent to a lab and tested for chromosomal abnormalities.
- ❖ Background information: the human genome has 46 chromosomes
- ❖ Aneuploidy = when a fetus has any number of chromosomes other than 46

# Issues in Disabled Community



## Accessibility

- ❖ There is not enough education about this topic
- ❖ Not enough adjustments to fit needs
- ❖ Not enough aid provided to the disabled parenting community.



## Discrimination

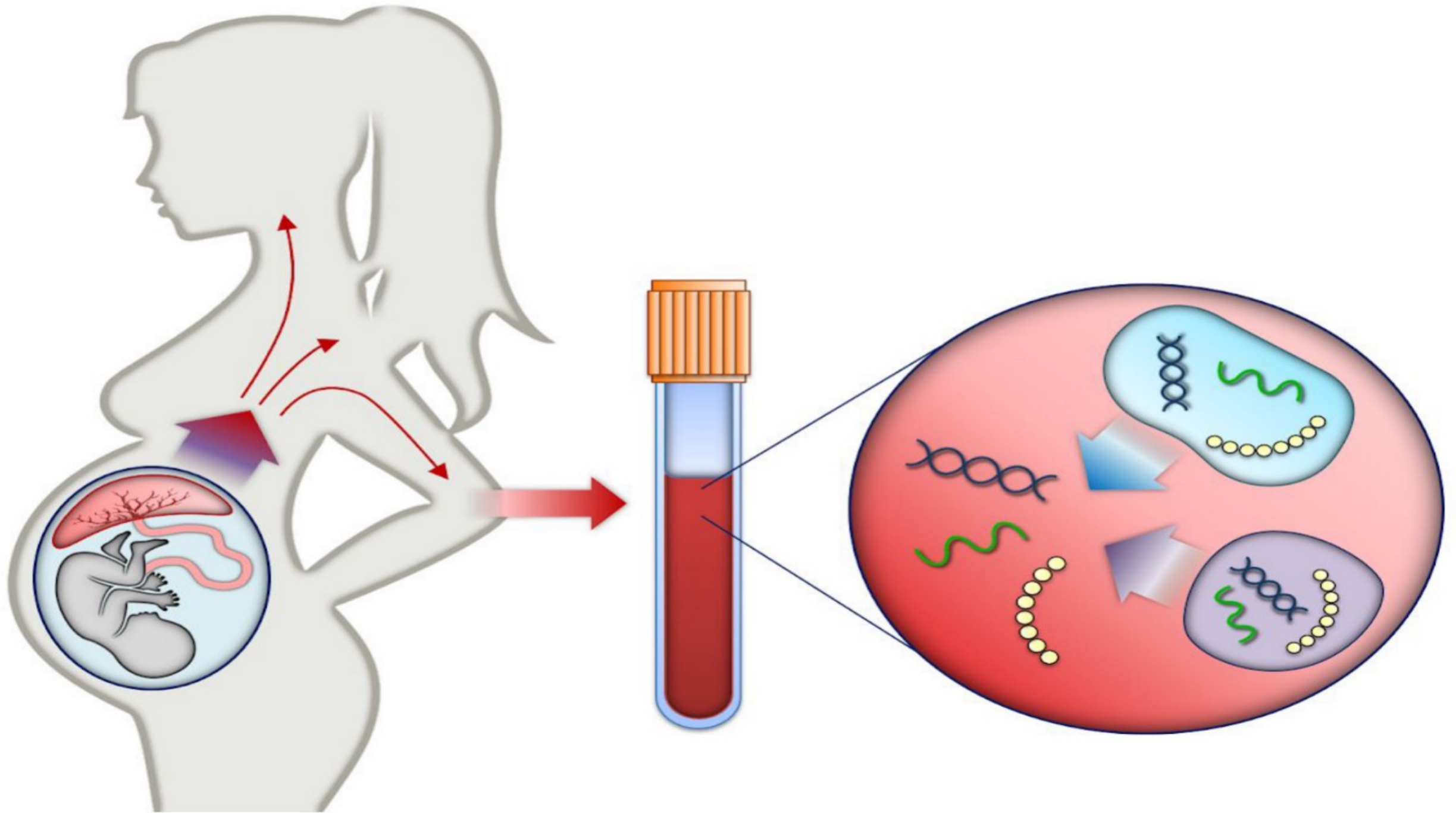
- ❖ Refuse treatment
- ❖ Laws and policies that seem neutral but negatively impact community.



## Abortion

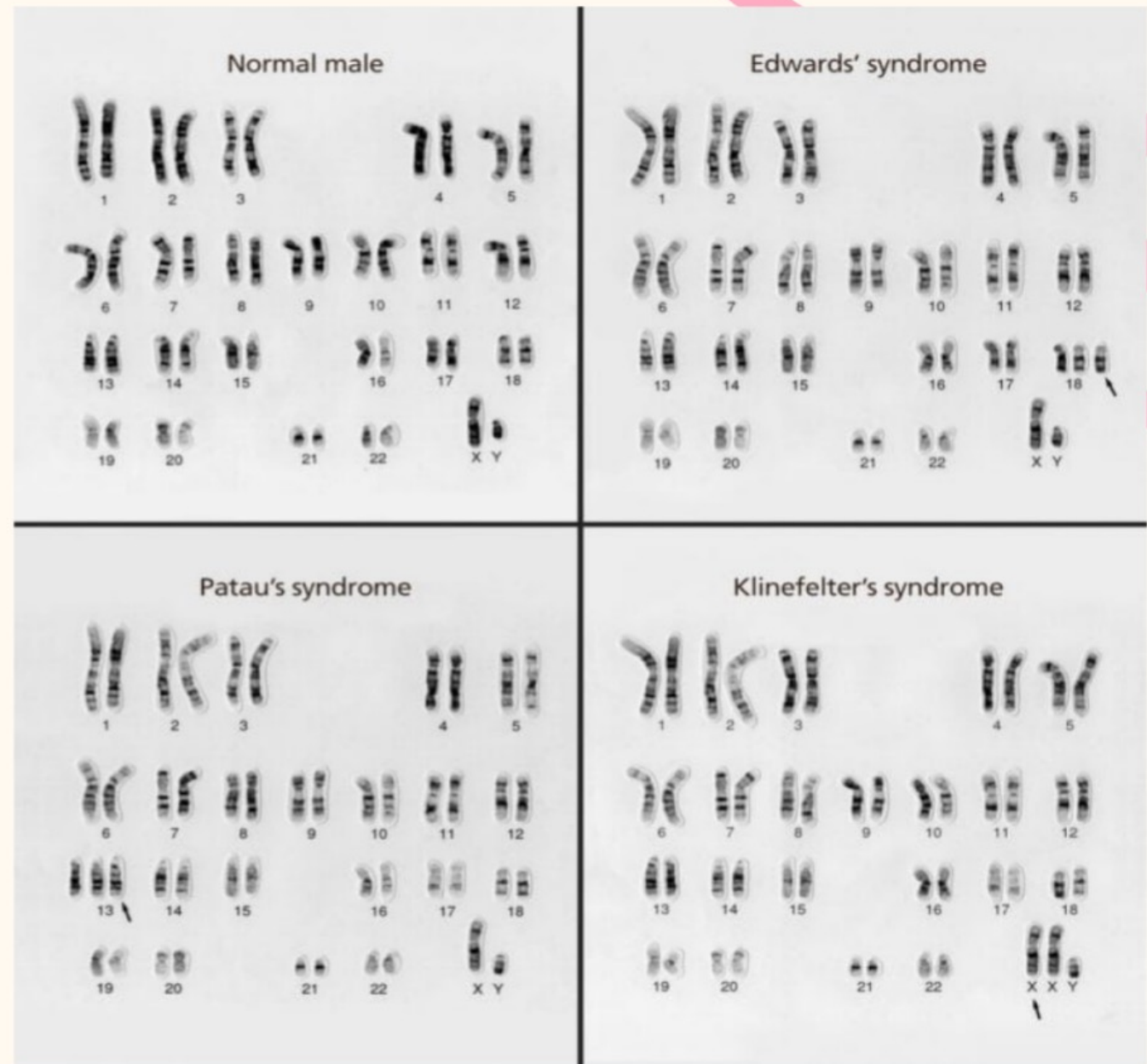
- ❖ If the results of the tests show that the fetus will not survive to full term, an abortion may be recommended.
- ❖ Little access
- ❖ Lack of education
- ❖ Anti-discrimination



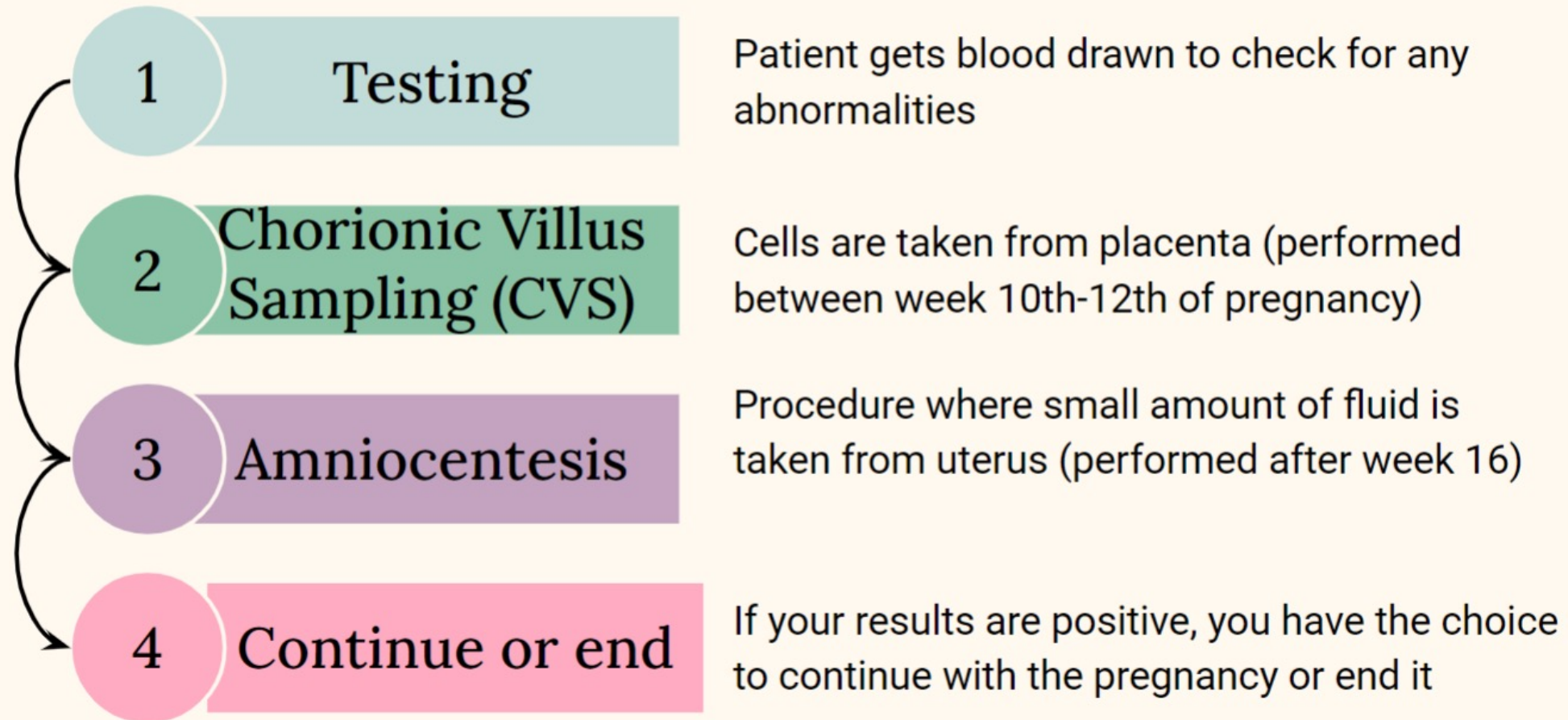


# Why??

- ❖ Helps find chromosome differences in fetus
- ❖ Available to all women
- ❖ This testing can prevent the mother from harm.
- ❖ Can help a family prepare their lifestyle for a child with a disability.



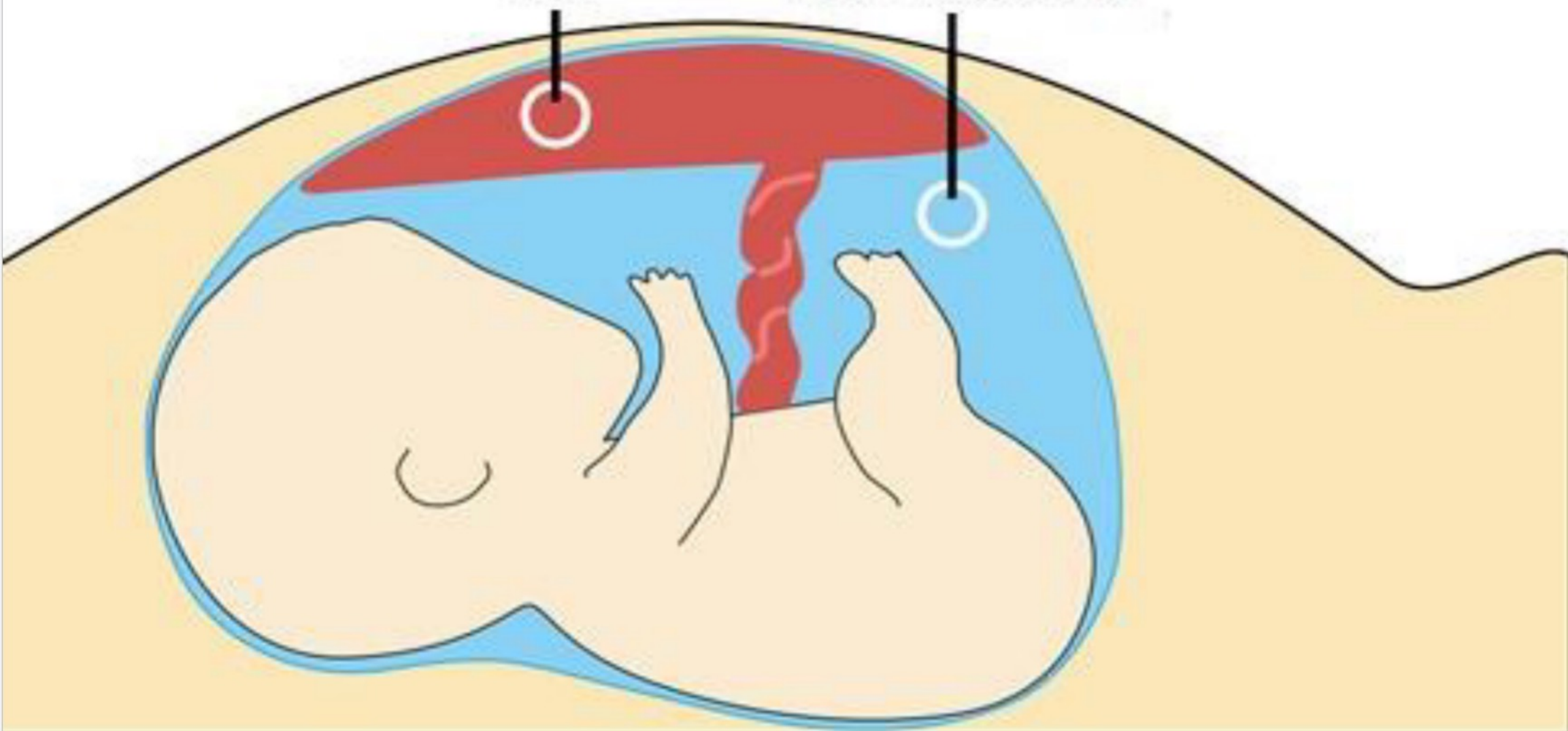
# Process





**CVS**

**Amniocentesis**



# Risks



## Fetus Alteration

Fetal limb damage if CVS is performed before the 10th week



## Inaccurate

Sometimes the NIPT test is a false-positive or a false-negative



## Pain

CVS and amniocentesis can be uncomfortable and even painful



## Miscarriage

Because testing can be invasive, there is a possibility of losing the baby



## Infection

Body does not respond well to foreign object being inserted

# Summary

Prenatal screening and testing for aneuploidy can be a hard process to go through: physically and mentally. Disabled expecting mothers have a different and harder experience than abled women. Some get dismissed or mistreated, even denied access. Screening includes testing for genetic differences while testing is the process that the biological sample goes through in the lab. These processes can provide expecting parents with further information about their baby and how they can best move forward with their results.





# Resources

- <https://www.mayoclinic.org/healthy-lifestyle/pregnancy-week-by-week/in-depth/prenatal-testing/art-20045177#:~:text=The%20two%20main%20types%20of,prenatal%20cell%2Dfree%20DNA%20screening.>
- <https://www.genome.gov/genetics-glossary/Aneuploidy#:~:text=Aneuploidy%20is%20an%20abnormality%20in,other%20than%20the%20usual%2046.>
- <https://my.clevelandclinic.org/health/diagnostics/21050-nipt-test>
- <https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Disability-Briefing-Paper-FINAL.pdf>



**Questions about  
prenatal screening  
and testing and  
people with  
disabilities?**



**Thanks!**

Question and Answers!!

# Right to parent

Alexis Herrera & Delanie Renteria





# Parental Rights

**It's not uncommon for people with disability to raise children of their own.**

**Taking care of a child is a big responsibility. But disabled parents have always been capable of being good parents.**

**So why are parents with disabilities set up to fail?**



# Concerning Facts

- In the U.S, 4.1 million parents have a disability.
- According to the National Council on Disability, the child removal rate is 80% for parents with disabilities.
- For parents with disability having their newborn baby permanently taken away is not uncommon.
- At least 13% of physically disabled parents have reported that they were treated poorly by Child Protective Services.





# Disabled Parents Have Rights and Protections

## What is the ADA?

The Americans with Disabilities Act (1990) is a law that does not allow people with disabilities to be treated poorly simply because of their impairment.

## How does the ADA protect disabled parents?

- Protect parents with disabilities from the bad practices of child welfare programs.
  - By requiring Child Protective Services (CPS) to judge disabled parents fairly.
  - Make CPS parental programs inclusive and accessible for all persons with impairments.





# Does the ADA prevent unfair child removal?

- Despite having parental rights, parents with disabilities are reported to CPS much more often compared to able-bodied parents.

## Why is this a problem?

- Disabled parents are permanently separated from their children, without any proof of harm toward the child needed.
- At least in 35 states, parents with disabilities get their parental rights taken away because of their impairment.
- This is wrong because it separates children from loving parents. We should not let others label disabled parents as unable to provide for a child's needs.



# Case Study: LaShondra Whaley

- Ms. Whaley is a disabled, single, Black mother
- Her son, J.W. was taken after someone reported her to Child Protective Services
- J.W. was placed in foster care because the state thought that she could not take care of him properly



# Court Decision



- The State of Tennessee said Ms. Whaley needed to be mentally evaluated and take parenting classes to get her son back
- Ms. Whaley won her case because there was not enough evidence against her
- The court said they had to move in with a friend from church, or else J.W. would be placed in foster care again



# Equitable Solutions

## Government Assistance



Create federal-funded programs to provide childcare assistance to parents with disabilities.

## Support System



Access to support groups that give new parents tips and tricks to take care of their child.

## Accessibility



Programs must be accessible to all disabled parents regardless of race, socioeconomic status, gender, and ability.

# References

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# Questions about the rights of disabled parents?

*Thank You So Much*



Alexis Herrera | Delanie Renteria



# Q&A

