Short Takes on disability and sexual and reproductive health
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
Overview of the Course
Defining Sexual and Reproductive Health
| Sexual health     | • positive and respectful approach to sexuality and relationships  
|                  | • possibility of having pleasurable and safe sexual experiences   
|                  | • without coercion, discrimination, or violence                   |
| Reproductive justice | • the right to have children                                      
|                    | • the right to not have children                                  
|                    | • the right to nurture the children you have in a safe and healthy environment |
| Disability justice | • cross-disability framework                                     
|                    | • values access, intersectionality, leadership of the most impacted, and wholeness |
# Short Takes

disability and sexual & reproductive health

<table>
<thead>
<tr>
<th>Topic</th>
<th>Students</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex Education</td>
<td>Hannah Bowes &amp; Marisol Mercado</td>
</tr>
<tr>
<td>Accessibility of health services</td>
<td>Joslynn Cruz &amp; Eli Whitaker</td>
</tr>
<tr>
<td>Contraception</td>
<td>Isaac Guevara &amp; Silence Jackson</td>
</tr>
<tr>
<td>Sexual Violence</td>
<td>Evelyn Canales</td>
</tr>
<tr>
<td>Prenatal screening and testing for aneuploidy</td>
<td>Lucia Gideon &amp; Robin Sunada</td>
</tr>
<tr>
<td>Right to parent</td>
<td>Alexis Herrera &amp; Delanie Renteria</td>
</tr>
</tbody>
</table>
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

1. Trust
   Educators must build trust with the disability community

2. Inclusivity
   Curriculum should be easy to understand for all

3. Access
   Sex education should be part of special education

4. Policy
   Officials must protect access to sex education for people with disabilities
References


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
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?

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

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

“They can create a big thing out of nothing.”
How accessible is healthcare now?

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

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

“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.”
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:

JOGNN Article:

Senate Bill 933:
Questions about accessibility of sexual and reproductive health services and people with disabilities?
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
- 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.
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.

NPR - Abused and Betrayed
Common Sexual Victimization Experiences

"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

Perceptions and Stereotypes

Harmful misconceptions contribute to sexual violence against disabled people.

“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

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

Pain and Awareness

Disabled survivors of sexual violence feel physical and emotional pain.

“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

“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

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

“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

- Received by Lauren Clark, Preventing and Addressing Sexual Violence Against People with I/DD, 30 Apr. 2024.
Questions about sexual violence and people with disabilities?
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

1. Testing
   - Patient gets blood drawn to check for any abnormalities

2. Chorionic Villus Sampling (CVS)
   - Cells are taken from placenta (performed between week 10th-12th of pregnancy)

3. Amniocentesis
   - Procedure where small amount of fluid is taken from uterus (performed after week 16)

4. Continue or end
   - If your results are positive, you have the choice to continue with the pregnancy or end it
<table>
<thead>
<tr>
<th>Risk</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fetus Alteration</td>
<td>Fetal limb damage if CVS is performed before the 10th week</td>
</tr>
<tr>
<td>Inaccurate</td>
<td>Sometimes the NIPT test is a false-positive or a false-negative</td>
</tr>
<tr>
<td>Pain</td>
<td>CVS and amniocentesis can be uncomfortable and even painful</td>
</tr>
<tr>
<td>Miscarriage</td>
<td>Because testing can be invasive, there is a possibility of losing the baby</td>
</tr>
<tr>
<td>Infection</td>
<td>Body does not respond well to foreign object being inserted</td>
</tr>
</tbody>
</table>
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.genome.gov/genetics-glossary/Aneuploidy#:~:text=Aneuploidy%20is%20an%20abnormality%20in%20other%20than%20the%20usual%2046.

- https://my.clevelandclinic.org/health/diagnostics/21050-nipt-test

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.


Questions about the rights of disabled parents?