

# Cultivating Healthy Relationships, Including Sexuality

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# Let's talk about SEXUALITY!



## Activity

In the chat box,  
type the terms you  
have heard used to  
describe sexuality.



# Objectives...

- Gain knowledge about sexuality and specific issues for people with developmental disabilities
- Learn AAP guidelines on menstruation and contraception for people with developmental disabilities
- Explore ways to communicate one-on-one about sexuality with people with developmental disabilities

# What is Sexuality?

Sexuality means more than intercourse or sex.

It's about intimacy, connection, and belonging.

It's about relationships- friendships and sexual relationships.

It's about how we feel about being the gender we are.

It's about how we feel about others and ourselves.

It's about sexual expression and behavior.

**It's the TOTAL of who we are, what we believe,  
what we feel, and how we respond.**

# Messages People with Developmental Disabilities Get Regarding Sexuality:

- Are not sexual beings
- Should not have sex
- Are innocent and childlike and need protection from sexuality
- Are not responsible
- Can not solve problems
- Are unable to make good decisions about sexuality
- Always make mistakes
- Would not make good parents so should not have children
- Are different than their non-disabled siblings

# Why Do People with Disabilities Need & Want to Learn About Sexuality?

Self advocates say....

- "So we can learn to have healthy relationships"
- "So we aren't lonely!"
- "So we are able to make informed choices!"
- "So we can pick the right person!"
- "For help with the toughest part of the relationship, making it last!"
- "So we can be safe!"
- "Because we all have desires/needs and that's okay!"
- "So that people know their rights!"
- "So we can be sexual self advocates, not just self advocates!"

# Three main barriers to provision of education



1. Perceived need to protect disabled adolescents and young adults
2. Lack of training and educational resources
3. Cultural prohibitions stemming from religious beliefs

*Lafferty, McConkey, Simpson 2012*

# Sexuality Awareness and Education is Also Important to Assure the Social Health and Safety of Individuals with Developmental Disabilities

## Key Findings from the 2018 NPR Investigation: *Abused and Betrayed*

- ▶ People with intellectual disabilities are sexually assaulted at a rate that's **SEVEN** times higher than those without disabilities
- ▶ The abuser is more likely to be someone the victim knows
- ▶ They are more likely to be assaulted during daytime hours
- ▶ People with intellectual disability are targeted due to vulnerability
- ▶ These crimes go mostly unrecognized, unprosecuted and unpunished.
- ▶ Police and prosecutors are often reluctant to take these cases because they are difficult to win in court.

## Sexual Assault Rates Among People With Intellectual Disabilities, 2011-2015

The rate of rape and sexual assault against people with intellectual disabilities is more than seven times the rate against people without disabilities. Among women with intellectual disabilities, it is about 12 times the rate.

### RATE PER 1,000 PEOPLE



### RATE PER 1,000 PEOPLE WITH AN INTELLECTUAL DISABILITY, BY GENDER



### Notes

Based on the noninstitutionalized U.S. residential population age 12 or older

Source: Bureau of Justice Statistics, National Crime Victimization Survey, Special Tabulation

Credit: Katie Park/NPR

# Human Sexual Development Continuum



Development of Biological Sex

Gender Assignment

Development of Gender Identity & Societal Gender Role

Development of Values and Attitudes About Sexuality

Physical and Emotional Changes of Puberty

Development of Sexual Orientation

# Human Sexual Development Continuum Cont.



Affectional Attraction

Romantic Attraction

Erotic Attraction

Development of Sexual Behavior

Development of Sexual Identity

Development of Sexual Knowledge

**Development of Sexual Skills**

# Individuals with Developmental Disabilities Need Sex Education based on their **BIOLOGICAL AGE**

A person's physical, cognitive and/or intellectual impairment does not impair his/her biological developmental needs



# Sexuality Interests & Concerns: Young Children

Body Parts & Functions

Genital touching, Sex Play

Reproduction: 'Where did I come from?'

Roles as male/female

Body Image

Need for Privacy Increases



# Sexuality Interests & Concerns: Adolescents

Physical Changes of Puberty

Masturbation

Hygiene

Sexual Orientation

Friendships

Gender Identity

Reproduction, Pregnancy, Birth,  
Pregnancy Options

Body Image

Sexual Expression

Establishing & Maintaining Intimate  
Relationships

Contraception & Sexuality  
Transmitted Infections

- Ways of expressing affection
- How to communicate with a partner
- Deciding about having sex
- Giving & receiving pleasure

Sexual Feelings

Breaking Up



# Sexuality Interests & Concerns: Adults

Pregnancy, Birth

Separation/Divorce

Parenting

Body Image

Contraception, Sexually Transmitted Infections

Menopause

Masturbation

Changes in sexual functioning

Sexual Orientation/Gender Identity

Establishing and maintaining intimate relationships

# Guidelines for Persons with IDD: Addressing sexual and reproductive health

## Menstruation and Contraception

1. Begin anticipatory guidance at the start of thelarche (breast development) which gives you usually a 2 -3 year interval for education.
2. Evaluate the adolescent's expectations and desires if possible
3. Menstrual suppression shouldn't be started before onset of menses - many adolescents do well with menstruation without any intervention
4. Contraceptive methods are US FDA approved only for birth control, and use for menstrual management is considered "off-label" but also standard of care.
5. ACOG recommends LARC methods as first-line contraceptive for adolescents (patients with IDD may need general anesthesia for placement)
6. Non-reversible methods and ethical implications

What ? Do ? We ? Do ? Now?

# General Tips on How to Discuss Sexuality with Individuals with Developmental Disabilities

- Leave your values out of the discussion
- Give POSITIVE messages
- Don't feel like you have to know all the answers
- It's OK to feel embarrassed
- It's OK to answer later
- Give facts and a range of opinions
- Be concrete, descriptive & use anatomically correct language (ex. penis or vagina vs. private part)
- Use repetition
- Ask the person if they have someone they feel they can trust to talk to or ask questions about sexuality



# Different Types of Questions Related to SEXUALITY

Factual, how to

What is a condom?

How are babies made?

How do I meet people?

Values, Opinions

Should I have sex?

What contraception should I use?

Personal

When did you start having sex?

Did you have sex last night



# Teachable Moment Format When ANSWERING Questions About Sexuality

1. Reassure the person that it is good to ask questions.
2. Find out what the person thinks/is really asking.
3. Decide what "messages" you want to give.
4. Answer simply, using correct vocabulary.
5. Encourage the person to give you feedback.

# Examples of How to Answer the Different Types of Questions Related to Sexuality

## Information



**What is birth control?**

**You give information. Keep it simple.**

“There are lots of different kinds of birth control and what they do is help people not get pregnant when they have vaginal sex”.

# Examples of How to Answer the Different Types of Questions Related to Sexuality

## **Advice** (opinions/values)



**Do you think it is okay to have sex before you are married?**

They are seeking out your opinions or values. It can be easy to answer this, but this doesn't help them. We need to help them figure out what they think



**“What do you think?”**

**“What is important to you?”**

# Examples of How to Answer the Different Types of Questions Related to Sexuality

## Personal



**How often do you have sex?**

It may be a way to get to know you better, but more likely it's to find out if they are normal.

### Activity

In your chat box, answer the following questions.

- 1) When is it ok to answer this question?
- 2) How would you answer the question?

# Scarborough Method- helpful tool to use when ANSWERING questions & explaining sexuality concepts

**Physical-** what it is, physical aspects

**Social-** private or public activity, responsibility, laws

**Emotional-** feeling connected to it

*\*\*\*Remember to give age appropriate, medically accurate information and create a safe learning environment*

Example: What is a condom?

**Physical-** a rubber sock that covers a man's penis

**Social-** using a condom is private; it protects you and your partner

**Emotional-** many people feel good when they use them because they are being responsible



# ASSESSING Sexual Behavior: What is the meaning behind the behavior?

- ▶ Structural
- ▶ Modeling
- ▶ Partner Selection
- ▶ Inappropriate Courtships
- ▶ Sexual Knowledge
- ▶ Learning History
- ▶ Perpetual Arousal
- ▶ Medical
- ▶ Medications
- ▶ Moral Vacuum

From Dave Hingsburger's Theory on Counterfeit Deviance

# Counterfeit Deviance Theory

- “Counterfeit Deviance” is defined as behaviors that appear deviant upon initial observation but can be attributed to factors other than deviant sexual arousal
- Regardless of the level of intrusive behaviors they are not always the result of deviant arousal
- Sexual misbehavior must be taken seriously, however, assumptions should not be made solely on the “look” of the offensive behavior
- The theory can also be expanded to include any type of criminal act in which a person who has developmental disability engages
- A comprehensive evaluation of the individual may be needed and should consider medical, psychiatric, psychological, habilitative, social, and environmental factors that could have influenced or contributed to criminal behavior

# ASSESS the Meaning Behind Sexual Behavior Before Addressing the Behavior

## Example

A woman with a developmental disability is using a pencil to masturbate and is hurting herself.

## Activity

In your chat box, answer the following questions

- 1) What could be the reasons for the behavior?
- 2) What approach might you use to address the behavior?

### Hypothesis

- Sexual arousal
- Discomfort
- Modeling

### Approach

- Sex education
- Medical check up
- Sex education

## Teachable Moment Format When RESPONDING to Behaviors & Comments Regarding Sexuality

1. Decide first if it is better to ignore the situation. If ignoring the situation is inappropriate, then continue with the following steps...
2. Name the behavior/comment to the person(s) as you see or hear it; praise if appropriate.
3. Find out the meaning of the behavior/comment to the person(s).
4. Decide what "messages" you want to give.
5. Give the messages by responding simply.
6. Encourage the person(s) to give you feedback.

## RESPONDING to Behaviors & Comments Regarding Sexuality

### Example

A young man masturbates in the bathroom at your clinic/school/agency. He locked the door to maintain privacy, but in there for almost 45 minutes. There is no other bathroom for others to use.

Can someone share their thoughts about what might be going on?

Can some share how they would you respond?

# Conclusion

- Sexuality is more than the act of sex- it is a sum of a person's total being
- Individuals with developmental disabilities need human development and sex education just as their typical developing peers
- When supporting the social and sexual health of individuals with disabilities we must reframe from imposing our values or viewing behaviors as negative or deviant
- Supporting the mental, physical, social and sexual health of all individuals is important for overall well-being and quality of life

# Sexual Health Matters

because

Sexual Health is Social Health



# Thank You

**Telehealth ROCKS**  
Rural Outreach for the Children of Kansas

**KU** PEDIATRICS  
The University of Kansas

# Resources

Abused and Betrayed: People with Intellectual Disabilities and an Epidemic of Sexual Assault

<https://www.npr.org/series/575502633/abused-and-betrayed>

AUCD resource on sexuality and sexual abuse and risk

[https://aucd.org/ECP/detail/event.cfm?event\\_id=2655](https://aucd.org/ECP/detail/event.cfm?event_id=2655)

Beyond Words- Empowering People through pictures <https://booksbeyondwords.co.uk/book-sets/relationships-mini-set>

Circles Curriculum <https://stanfield.com/product/circles-curriculum-bundle-w1004-38/>

Sexuality and Developmental Disabilities by Katherine McLaughlin [www.elevatustraining.com](http://www.elevatustraining.com)

The Healthy Bodies Toolkit <https://vkc.mc.vanderbilt.edu/healthybodies/>

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