

Sexuality, Self-Determinism, and Sensibility

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Disclosures

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Learning Objectives

At the end of the session, participants will:

- 1. Recognize how the cultural constructions of sexuality and of disability can influence the sexual lives of individuals with intellectual or other developmental disabilities;
- 2. Value the importance of self-determinism as a foundation for healthy sexuality; and
- 3. Identify strategies to promote sexual health among individuals with intellectual or other developmental disabilities and with their caregivers.







What is sexuality?

Take a minute to think about how you would describe sexuality. Jot down a few words or phrases if that would be helpful.







"Sexuality is not synonymous with sexual intercourse, it is not about whether we have orgasms or not, and it is not the sum total of our erotic lives. Sexuality is so much more: it is the energy that motivates us to find love, contact, feel warmth, and intimacy; it is expressed in the way we feel, move, touch and are touched; it is being sensual as well as sexual."

The World Health Organization (1975)



- Sexuality is constructed, and it's complex.
- Everyone has sexuality.
- Sexuality is developmental and dynamic.
- Sexuality is personal and self-determined.
- At a minimum, sexual behavior should be consensual, responsible, and healthful.



- Sexuality is constructed, and it's complex.
 - There are rules.
 - There is ambiguity.
 - There is history.
 - It is encompassing.
 - It is personal.
 - It is collective.
 - It is influenced by many factors.



Sexuality Influences

- Beliefs
- Attitudes
- Behaviors
- Values
- Norms
- Language
- Practices
- Policies

- Knowledge
- Situation
- Location
- Intellect
- Parenting
- Role Models
- Culture
- Education

- Experience
- Media
- Self-esteem
- Religion
- Emotion
- Socialization
- Disability
- Skills
- Etc.



- Everyone has sexuality.
 - A long history of segregation, an emphasis on functional integration, and disability centered services have contributed to the cultural construction of disability and the perception of sexuality and disability.
 - This perception has perpetuated myths about persons with intellectual or other developmental disabilities and how they experience their sexuality.



Sexuality Myths



Persons with intellectual disabilities...

- Are not sexual, or they all are asexual.
- Are not interested in sexual relationships.
- Are not desirable.
- Are not appropriate partners.
- Are not sexually exploited or assaulted.
- Are not able to initiate, enter into, or maintain intimate relationships.
- Should be abstinent unless married.



 Sexuality occurs developmentally and changes throughout the life span.

- Infancy (Ages 0-2)
- Childhood (Ages 3-11)
- Adolescence (Ages 12-19)
- Early Adulthood (Ages 20-40)
- Middle Adulthood (Ages 40-60)
- Late Adulthood (Age 60+)

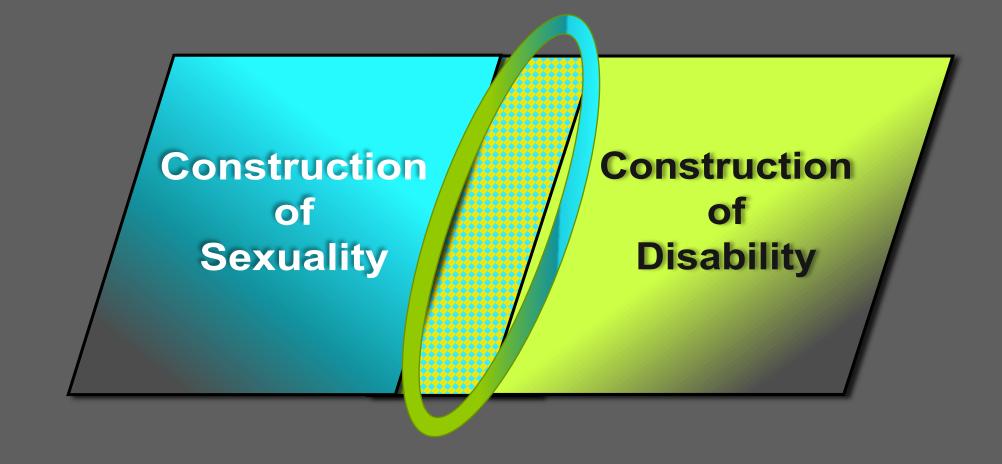
There is an assumption physical, intellectual, and psychological development will be typical as one ages.



- The perceived difference between age and development of the individual can influence how sexuality is approached and addressed, such as...
 - Ignoring or dismissing sexuality
 - Need to know basis approach (e.g., basic anatomy, hygiene, etc.)
 - Restrictive policies
 - Reactive rather proactive practices
 - Risk promoting policies, practices, and programs



Sexuality and Disability





Sexuality and Disability

What influences our perceptions of disability and sexuality?

- Preoccupation with physical perfection
- Gender expectations and stereotypes
- Dysfunctional view rather than diversity (e.g., language, education, services, etc.)
- Focus on limitations





- Sexuality is personal and self-determined.
- Self-determinism opportunities to decide who to be, how to behave, and what to become that require:
 - Problem solving
 - Choice making
 - Goal setting
 - Self-regulation
 - Self-advocacy
 - Self-belief
 - Goal attainment
 - Self-awareness

Note the skill emphasis!



What is **challenging** about sexuality and self-determinism for individuals with intellectual or other developmental disabilities?

- Cultural construction of sexuality and of disability within society, health services, and education
- External challenges because of disability (e.g., disability centered services that ignore sexuality, lack of professional training, lack of accommodations, etc.)
- Providing protection while affording equality
- Risk factors for sexual consequences



Risk factors:

- Lack of knowledge about sexuality
- Lack of relevant sexuality education experiences
- Lack of typical social experiences
- Low self-esteem
- Eager to be partnered
- Eager to please others
- Sheltered by parental protections
- Lack of opportunities to sexually express
- Expectations of sexual independence



- A sexually healthy adult has both knowledge and skills.
- Skills can be a protective factor to help individuals with intellectual or other developmental disabilities navigate and negotiate their sexuality.
- Sexual health promotion then, must be a skills based approach that begins at an early age, that is repetitious throughout the life span, and that affords practical application using realistic sexual situations in their learning experiences.
- Sexual health promotion must be developmentally appropriate as well as age appropriate.
- Sexual health promotion should be strength based.



Self-Determinism

- Problem solving
- Choice making
- Goal setting
- Self-regulation
- Self-advocacy
- Self-belief
- Goal attainment
- Self-awareness

Skills

- Conflict Resolution
- Decision making
- Goal Setting
- Communication
- Assertion
- Refusal
- Help Seeking



Supported Decision Making Model

- Supported decision making means helping a person understand, make, and communicate his/her own decisions.
- Assumes everyone has capacity for
 - Self Determinism
 - Self Advocacy
 - Self Actualization



WHO Sexual Health

- Sexual health is the state of physical, emotional, mental, and social well-being related to sexuality, and not merely the absence of disease or dysfunction.
- Sexual health requires a positive, respectful, and consensual approach to sexuality and sexual relationships.
- Sexual health requires the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, violence, and disease.









- It's important to start with their story, their truth about their sexuality.
- Utilize a strength based approach in helping them understand their sexuality.
- Recognize the limitations they might be experiencing are not about their disability per se, but about the limitations that exist in a world without many meaningful accommodations for their sexual development.
- Respect their rights to define their sexuality, sexually express, and learn about sexuality.



- At a minimum, sexual behavior should be consensual, responsible, and healthful.
 - Behavior is learned, and so is sexual behavior. Individuals with intellectual or other developmental disabilities tend to behave "inappropriately" because they haven't learned cultural scripts for acceptable sexual behavior.
 - Also keep in mind their perceptions of the benefits to barriers ratio might be different than our professional perceptions.

How can we assist individuals with intellectual or other developmental disabilities achieve consensual, healthful, and responsible sexual behavior?

enhancing

- Sexual Risk Reduction: targeted approach to specifically teach how to avoid negative sexual consequences, such as STIs, HIV, unintended pregnancy, sexual assault, etc.
 - This focus on the negative aspects of sexual behavior can encourage the development of negative attitudes about sexuality, resulting in fear, uncertainty, and shame.
 - An outcome can be erotophobia or a more negative emotional response to sexuality-related situation.



 Sexual Health Promotion: sex positive approach that teaches how to avoid negative sexual consequences AND how to develop healthy sexuality, such as identity acceptance, sensuality, sexual diversity, etc.

Sexual health promotion includes sexual risk reduction, but sexual risk reduction is not necessarily sexual health promotion.



Sexual health promotion should include:

- Functional information
- Skills emphasis
- Planned repetition of information
- Application of information and practice
- Reality based (Relevant, Real, Right Now)
- Adaptive and/or accommodated
- Active engagement
- Sex positive messages
- Proactive approach



Sexual Health Promotion With Caregivers

- Advocate that sexuality education begin early and occur often with their children.
- Encourage them to accept their child as a sexually developing individual.
- Reassure them their child's sexuality isn't "abnormal" just because they have a disability; what their child is experiencing is probably typical.
- Enable them to be proactive in their approach to their child's sexual development rather than reactive to sexual incidents.



Sexual Health Promotion With Caregivers

- Be sex positive in your discussions with caregivers.
- Provide sexuality resources for caregivers that are useful, accurate, and CURRENT.
- Acknowledge when you don't know the answer.
- Role play approaches with caregivers.
- Model calm when discussing sexuality; your calm will help them develop comfort.
- Seek professional development regarding sexuality and disability.

Sexuality, Self-Determinism, and Sensibility



- Questions
- Thoughts
- Comments

