



Sexual Health and Individuals with Intellectual Disabilities & Autism

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Objectives

At the conclusion of this presentation, you should:

- Have knowledge about how to comfortably address sexual health with a person with IDD.
- Understand the risks of neglecting sexual health as an integral educational concept for people with IDD.
- Be able to identify characteristics of a person with IDD who has been sexually abused.



Transition Planning

**Creating a lasting,
satisfying, person-
directed, quality of life.**



Transition Planning

**One critical area that is
often not addressed...**

(even in healthcare transition planning)



Sexual Health ²¹

- Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.
- Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.
- For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.



FACT or FICTION



FACT or FICTION? ²²

30 years ago preventive health concerning sexuality of people with IDD was addressed through surgical sterilization as part of nationwide programs in many Western countries.

FACT: In 1982, 67% of Canadian parents of children and young adults with IDD favored the practice of voluntary sterilization, particularly for those with severe IDD.



FACT or FICTION? ²³

People with IDD are likely to have the same range and desire for sex and relationship needs as adults without disabilities.

FACT: A person with intellectual disability is likely to have the same range of sexual and relationship needs as other adults. However, there may be multiple barriers to forming healthy, equal sexual relationships. ²³



FACT or FICTION? ³

If people with intellectual disabilities are protected and kept away from strangers, they will be safer from sexual abuse.

FICTION: Most young people with IDD are sexually abused by those they know and trust. Perpetrators are most often those who are known by the victim, such as acquaintances, residential care staff, transportation providers and personal care attendants. Therefore, the service system created to meet specialized care needs of those with IDD contributes to the risk of sexual violence.



FACT or FICTION? ²⁶

After people with intellectual disabilities are educated about their sexual health, it is hard for them to control their sexual urges.

FICTION: People often think that when individuals with IDD people educated about their sexual health, then they become 'oversexed' and have 'uncontrollable urges'. The reality is that education and training are key to promoting healthy and respectful sexual behavior, regardless of the person's abilities and disabilities.



FACT or FICTION?

24

It is uncommon for individuals with IDD to be arrested and charged with a sexual offense.

FICTION: People with IDD are frequently being charged with a sexual offenses for inappropriate sexual behaviors such as public masturbation. It's critical to differentiate sexual deviance from sexual inappropriateness.



FACT or FICTION? 23

There is the exception. Some individuals with IDD don't really need sex education because they have a very low IQ, intense support needs, and will always remain childlike.

FICTION: While some believe that some individuals with IDD are somehow unable to participate equally in an intimate relationship, those with IDD are neither asexual nor childlike. Some individuals may not have the same words or actions to describe what they feel or desire, but their emotions and needs are very real.



The Reality

- Sexuality is not widely discussed.
- Why?
 - ✓ Considered taboo
 - ✓ Not seen as a real issue
 - ✓ Fear
- People with ASD have sexual needs and tendencies just as any other person does.



The Consequences

Victims who have some level of intellectual impairment are at the highest risk of abuse²

- >90% of people with developmental disabilities will experience sexual abuse at some point in their lives¹
- 49% of people with intellectual disabilities will experience 10+ sexually abusive incidents²
- Other studies suggest that 39-83% of girls and 16-32% of boys will be sexually abused before their 18th birthday³
- Rape likelihood: 15,000-19,000 people with developmental disabilities are raped each year in the United States⁴



The Consequences

- Individuals with developmental disabilities (includes intellectual disabilities, autism, cerebral palsy, epilepsy and learning disabilities) sexually assaulted 10.7x more than individuals without disabilities.
- ~55,000 children in Nebraska with intellectual disabilities were 4x as likely as children without disabilities to be sexually abused.⁵
- Study with 95 adults with DD: 83% of the women and 32% of the men had been sexually assaulted.
- **Only 3% of sexual abuse cases involving people with developmental disabilities will ever be reported¹.**



Sexual Abuse Vulnerability Factors⁶⁻¹⁰

VICTIMS WITH IDD

- **Powerlessness:** not given the power to make choices for themselves
 - Compliance to caregivers is reinforced
- **Need for personal care:** little control over who touches their bodies, and in what manner
- **Isolation:** often segregated from people without disabilities:
 - Increases likelihood of sexual abuse and likelihood that the abuse will go unreported
- **Physical defenselessness:** limited ability to protect him/herself



Sexual Abuse Vulnerability Factors⁶⁻¹⁰

VICTIMS WITH IDD

- **Language, speech, or vocabulary barriers:** difficulty protesting offenders, asking for help, or disclosing abuse
 - puts sexual abuse victims with disability at risk for further sexual abuse
- **Impaired or limited cognitive abilities**
- **Lack of abuse prevention education:** difficulty understanding and recognizing abusive situations



Teaching sexual health

**You must
START BEFORE...
PUBERTY Begins!**



Teaching Sexual Health

- A person with IDD is never too young to learn proper names for body parts, including genitals, or about 'public' and 'private'.
- In general, parents/caregivers/educators should look out for times when the individual expresses interest or curiosity in sex. For example: if they see actors kissing in a movie on television and start asking questions.



Teaching sexual health

- Sexual health education is an ongoing process, not a single lesson or lecture. The person should be given basic information first.
- Some topics are appropriate for group/social settings:
 - ✓ social relationships, feelings, conversation skills, complementing
- Most topics are best taught one on one:
 - ✓ distinguishing private/public, bathing, sexual feelings/sex/sexual abuse/, masturbation, menstruation, puberty/body changes



A Story with a Lesson¹²

- A professional in the intellectual disability field meets a man in his 40s with IDD. The man is with his parents.
- Man with IDD wants a hug, man in the field refuses, parents infuriated.
- After a discussion, parents realize they taught their daughter social trust skills, but son would hug just about anyone.

Never saw their son as an adult!



“Stranger, Danger” Issues

“Stranger, Danger” *not* the answer!

- 97-99% of abusers are service providers known and trusted by the person with the disability.
- Failure to teach those with IDD how to properly act on their urges can cause major issues in their future:
 - ✓ unacceptable public displays
 - ✓ unwarranted sexual harassment



Sexual Health Education & IDD

- Proper sexual relationships should be linked with self-care, self-protection, pleasure, and affection.²⁰
- If having received quality sexual health education throughout their life, sexual abuse rates are reduced; HOWEVER, the possibility is always evident.
- **In addition**, those with IDD who have been sexually abused themselves are at increased likelihood to become a sexual abuser in the future.



Key concepts for the initial “talk” & ongoing discussions

For Females

- Typical body changes (breast & hair development, acne, body odor)
- Menstruation
 - ✓ Should be celebrated (becoming a woman)
 - ✓ Prepare for sight of blood
 - ✓ Encourage calendar use and changing schedules
- Importance Preventive Health Screening
 - ✓ Pap smears & Pelvic Exams
 - ✓ Breast Exams

For Males

- Typical body changes (height & muscle development, hair, acne, body odor, voice drop)
- Spontaneous erections and wet dreams (and “erection management strategies”)
- Importance Preventive Health Screening
 - ✓ Prostate care
 - ✓ Testicular Exams



Tips for Teaching Sexual Health

Create a general list of most important things the individual needs to understand such as:

- Be concrete: “penis/vagina” NOT “birds & bees”.¹¹
- Teaching modesty: “my body is mine”.¹³
 - ✓ “Private part”: no touching or looking without permission
 - ✓ Private clothing: no touching or looking without permission
 - ✓ Private activity: done behind closed doors
- When person makes a mistake, direct your reaction to behavior.¹⁴
 - ✓ Redirect inappropriate behavior¹¹
 - ✓ Caregiver must analyze what can be different in the same situation to prevent future occurrences



Teaching Tips²⁰

- “Relationship staircase”: as time goes forward, relationships may escalate.
- Masturbation: assign a “private room” and affirm that *private acts* occur only in *private rooms*.
 - ✓ Try to remain normal and calm
 - ✓ Teach *private time*
- Intercourse/reproduction: *loving sex* is done in *private* between two *consenting adults*.



More about masturbation

- Masturbate in bedrooms???
- Often require visual stimulation (especially men).
- Solution



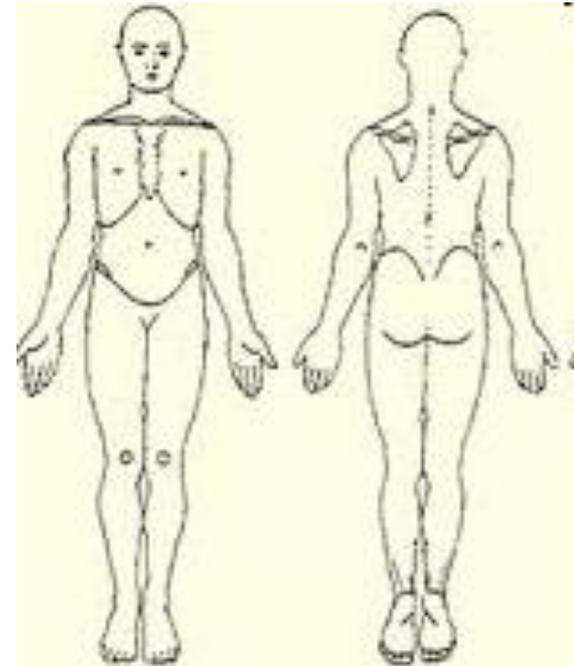
Teaching & Communication

Tips

- Be proactive, and use many teaching modalities.
 - ✓ Simple, visual, individualized, repetitive, fun, concrete
- Teach tasks in simple steps.
- Use a *calm matter-of-fact tone* and a “private voice” when discussing sexuality.

Teaching Strategies

- **Visuals-Pictures & collages:**
 - ✓ Demonstrate situations, ideas, acts, emotions, and ANYTHING relevant.
 - ✓ Body charts.
 - ✓ See teaching.
 - ✓ Tools in appendix.





Abuse Prevention²⁰

- Replace “*stranger danger*” with awareness of “*strange behavior*”.
- People in the world (even familiar ones) can do bad things.
- Body ownership / modesty / “my body is mine”.
- Encourage telling about abusive situations.



Signs of Sexual Abuse in Victims with IDD

- **Physical**
 - ✓ Difficulty walking or sitting
 - ✓ Bruises/pain in genital area
 - ✓ STDs
 - ✓ Headaches/stomachaches

- **Behavioral/psychological¹⁹**
 - ✓ Boundaries-related
 - ✓ Affect-related
 - ✓ Changes in socialization pattern

- **Changes in living skills**
 - ✓ Boundaries-related
 - ✓ Affect-related
 - ✓ Changes in socialization pattern



Signs of Sexual Abuse in Victims with IDD

- Changes in emotional stability
 - ✓ Boundaries-related
 - ✓ Affect-related
 - ✓ Changes in socialization pattern

- Changes in sexual expression
 - ✓ Boundaries-related
 - ✓ Affect-related
 - ✓ Changes in socialization pattern



Parents with IDD ²⁵

- There are approximately 36,500 parents with IDD in the United States.
- They often have difficulty understanding and responding to their children's needs.
- Most have low incomes, limiting their children's access to important developmental activities.
- Depending on the cause of the parents' disability, their children may be at increased risk of having an intellectual disability.
- Children who do not have intellectual disability may surpass their parents' cognitive ability at a young age. However, such children are generally positive about their parents and good outcomes are possible with appropriate support.



Helpful Resources & Materials

- **Appendix: References**

- **Teaching Tools:**

- Sexuality Across the Lifespan Workbook-Educators*

- <http://flfcic.fmhi.usf.edu/Content/Educator%20Low%20Res,English.pdf>

- Sexuality Across the Lifespan Workbook-Parents/Caregivers*

- <http://flfcic.fmhi.usf.edu/Content/Parent%20Low%20Res,%20English.pdf>

- Sexuality & Disability: A Guide for Parents*

- http://www.teachingsexualhealth.ca/media/pdf/Sexuality_Developmental_Disability.pdf



Key Points

- Those with IDD at an increased risk for sexual abuse.
- Sexual health must be taught to those with IDD from an early age.
 - ✓ Be concrete and visual.
 - ✓ Teach privacy, modesty, & self-acceptance.
 - ✓ Educate about inappropriate behaviors, do not punish.
 - ✓ Address preventive health needs,
- “Stranger danger” not effective in avoiding sexual abuse.
- Sexual health education is an ongoing process.



What can **YOU** do?

Take time to plan at least **one thing** you can do with the information you learned from this presentation.



Q&A

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This webinar will be online by November 1 at:
<http://flfcic.fmhi.usf.edu/projects/webinars.html>