Relationships and Sex Education: Rights vs Risk
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Rights for persons diagnosed with IDD/ASD

Sexuality

Rights for persons with IDD/ASD cont.
What are persons with IDD saying?

Department of Disability and Human Development - University of Illinois at Chicago: Sexuality & Disability Consortium:

- “I have the right to do stuff like have friends over.”
- “Don’t discredit my decision making.”
- “Saying what I will or will not consent to in an intimate relationship while attending to the needs of my partner.”
- “Professionals sometimes scared to talk about it because they don’t know what’s appropriate to say.”
- “We need education classes.”
- “It would help if you had diagrams. You know, like the male part and the female part.”
- “It is important to teach a health talk.”
- “What to do with females. Safety sex.”
- “Counseling information about how to inform people about sex.”
- “People like us need to have relationships too.”

What are persons with IDD saying?

Self Advocates Speak Up About Sex - Sexuality and Developmental Disabilities Workshops with Katherine McLaughlin

- Who first explained sex to you:
  - My parents, then my friends a bit more, much more detailed discussion
- I learned about sex in a sex education class:
  - I got the talk from my cousin. He said this is what it is, now go do it.
  - Seriously, I've never gotten the talk.
- What do you wish adults would've told you but didn't:
  - I wish they had given me an introduction to puberty.

Questions to think about

- Have you ever been in a relationship?
- Were you in a relationship before you were 18?
- Did you date, hold hands, kiss, have sexual relations before the age of 18?
- Who made the decision of whether you could do those things?
- Close your eyes and envision your life never having been liked, never having those first date butterflies, never having been touched, been kissed, never being in a significant relationship, getting married, having children. How would that feel? Would your life feel complete?
National Crime Victim Survey

Highlights:
- During the 5-year aggregate period from 2011 to 2015, for each age group measured except persons age 65 or older, the rate of violent victimization against persons with disabilities was at least 2.5 times the unadjusted rate for those without disabilities.
- Among those with disabilities, persons ages 12 to 15 (144.1 per 1,000 age 12 or older) had the highest rate of violent victimization among all age groups measured.
- The rate of violent victimization against males with disabilities was 31.8 per 1,000, compared to 14.1 per 1,000 males without disabilities.
- For females with disabilities, the rate of violent victimization was 32.8 per 1,000, compared to 11.4 per 1,000 females without disabilities.
- Males and females had similar rates of total violent victimization in every disability type measured, except independent living disabilities.
- https://www.bjs.gov/index.cfm?ty=pbdetail&iid=5986

What is Consent?

- Consent: when someone gives permission, or says “yes” for something to happen or gives an agreement to do something
- Consent must be voluntarily given
- Consent may be withdrawn at any time, for any reason, by any party involved

How is consent determined?

- Consent is determined by someone freely, outwardly expressing in an unambiguous communication an agreement to participate in something
- It can NOT be assumed by:
  - Body Language, Wardrobe, Location
  - Previous Activity
  - Dating/Marriage/Relationship Status
  - Silence, Passivity, Lack of Resistance, or Immobility
The Importance of Discussing Sexual Nuances: What Parents, Educators and Disability Service Providers Need to Know

– Beverly L. Frantz (Director of the criminal justice and sexuality initiatives at the Institute on Disabilities, Temple University)

- Daryl told staff when he turned 30 he was going to have sex. When he was a teenager his parents said he could have sex after 30 to delay talking about this uncomfortable topic. They thought he would forget about it. Could have had negative consequences as he wasn’t given other information about what and how this meant.

- Sexual expression is a natural and central aspect of humans.

- Change to person-centered, inclusion, rights and responsibilities

- Sexual nuances – subtle distinctions that often go unnoticed by family members, educators, and professionals.

- *James, a male student with Down syndrome made the football team - chest bumping, snapping a rolled towel against the backside, slapping another person’s naked butt. Engaging in these behaviors in other settings without discussing it could result in a criminal act.

- *Dylan - a boy with Autism attended public elementary in a self-contained class with a bathroom in the classroom. He was always told to “stay in line” in other school activities. He transitioned to middle school, went into the bathroom saw another student at the urinal. He went to urinal closest to the student and looked at him and said “Wow, nice penis”. He filled in the gaps, started conversation, complimented the peer based on what he was taught. He was accused of sexual harassment. The student wasn’t bothered however the teacher overheard him telling someone about his experience.

- *Yvette, 20 year old, worked evenings at a local mall. She successfully took public transit for years. One night the bus driver offered to drop her closer to home if she waited for everyone to get off the bus. He said things like, “This is what friends do”. Such a pretty girl should be careful walking home at night”. She trusted him. Eventually, he asked for a goodnight kiss - “That’s what friends do”. That eventually led to fondling and oral sex. One night she said no and he said “It’s our special place, our secret”. She was afraid to tell anyone and ended up quitting her job, refusing to take the bus and stayed in her apartment, and blamed herself for what occurred.

Stats
- CDC estimates that about 1 in 6, or 15% of children between the ages of 3-17 are diagnosed with one or more developmental disability
- Guttmatcher Institute reported 22% of adolescent males and 15% of adolescent females with a mild Intellectual Disability were not reported to have learned about reproduction and sexual health in school and the percentage of individuals lacking sexual education continues to rise as the level of their disability increases in severity
- State is moving to inclusion for day programming and school. What does that mean for these individuals? Can we continue to keep them in a bubble?
Adolescents with ID have increased difficulty when facing choices to engage in at-risk and offending behaviors as they may not understand the social, environmental, and legal consequences. These individuals are more vulnerable to this with increased inclusion in general academic settings. They may have limited understanding of the health detriments associated with substance use, sexuality, abuse, and legal rights. Adolescents with mild ID engage in risk-taking and offending behaviors at a higher rate than adolescents with moderate/severe ID. Research found that individuals with ID who participated in a social/life skills classes decreased the likelihood of engaging in risky/offending behaviors.
The body and sexuality
- Music videos - is this where we learn how to move our bodies and dance? When we get positive feedback from others - laughing, smiling, verbalization - what message does that
- Commercials - while they may not fully hold our attention and seem to be a break between shows...maybe we go to start dinner or fold laundry...the visual stimulation and actions shown create a physiological response and obtain the attention of our loved ones who may have difficulty discriminating between relevant and irrelevant details. Or, this may be something the person looks forward to. (movie stars...girls' night/boys' night out)
- Imagine seeing this material, feeling a response, and not having the dialogue to understand what is going on as well as experiencing negative responses to natural behaviors:
  - Masturbation
  - Hugging
  - Trying to kiss others
  - Dancing close
  - Petting up
  - Taking undergarments of a family member

The body and sexuality
- Body sensations - they occur whether we talk about them or not. Understanding of these messages helps to determine what to do and how to feel about them.
- Are individuals with disabilities inherently asexual?
  - Lack of opportunities and experiences can contribute negatively to gender identity, friendships, self-esteem, body image, emotional growth, and social behavior
  - Individuals may engage in sexual activity as a result of poor options, manipulation, loneliness, or physical force rather than as an expression of their sexuality
  - *AAIDD and The Arc Joint Position statement
- Puberty to aging:
  - How does the body change over the years?
  - How do people’s behaviors change over the years?
  - Puberty and aging are confusing enough for those individuals who anticipate these changes and cognitively may be able to understand why they are experiencing these emotional and bodily changes (how has it been for you?)
Puberty & IDD/ASD

- Physical and sexual development likely to be at the same time as their peers
- Similar to other adolescents, the person often has a desire to express their sexual feelings
- The person may have difficulty expressing what is happening to their body
- The person may experience anxiety about the changes
- They may experience differing ability to understand their changes and feelings

Puberty & IDD/ASD

- The person may require more education due to difficulty with understanding and communication
- Increased risk of sexual harm:
  - Lack of knowledge
  - Misinformation from peers
  - Lack of ability to understand the changes
  - Increased dependence on others for assistance
  - Tendency to be overly compliant
  - Lack of assertiveness training
  - Overprotected lifestyle and limited social contact

Puberty & IDD/ASD

- Difficulty learning about sex education:
  - Learning often at a slower rate
  - Communication issues
  - Limited literacy skills
  - Difficulty with abstract thinking and comprehension
  - Trouble relating the ideas to their own life experience
- Physical disability additional issues:
  - Impotence
  - Muscle contractions interfering with masturbation
  - Limited sexual sensation but still feel sexual desire and arousal
  - "Phantom" organ in other parts of the body
  - Muscle cramps during sex
Why talk about puberty and sexuality?
STI's
Unplanned pregnancy
Sexual abuse
Criminal issues
Victim becomes offender issues
Media/exposure

So...what do we do about it?
- http://www.qolcurriculum.com
- http://www.livingwithautism.com
- http://www.parentbooks.ca/Sexuality_&_Disability.html
- http://www.med.umich.edu/yourchild/topics/disabsex.htm
- http://autismnow.org/articles/resources-for-learning-about-sexuality/#Books

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