Sexual Behavior and Young Adults with Autism and Developmental Disabilities

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For Today’s Discussion

DD = Developmental Disability

includes individuals with cognitive and/or significant social delays, such as mental retardation, Down syndrome, cerebral palsy, fetal alcohol syndrome, and Autism/Asperger’s

 Teens = Adolescents = Young adults

Use of these terms today are interchangeable and generally refer to individuals around 13-20’s
Sound Familiar?

Daniels’ parents were called to school and told that a classmates parents were considering calling the police because Daniel’s ‘unwanted advances’ including touching her hair. During class today, Carrie had her hands down her pants and appeared to be rubbing her private parts.
Sound Familiar?

Craig stares at female classmates and teachers chest area for extended periods of time. Students complain of feeling uncomfortable in his presence as a result.
Sarah mistakes sexual advances from others as a way to make friends.
David was suspended for accessing and viewing pornographic websites on a school computer.
Sexuality education with individuals with intellectual and social deficits can be challenging because......
The complex social dimensions of sexual behavior
Differentiation between public vs. private or reality vs. fantasy
Ensuring maintenance and generalization of learned skills into “real life” settings
Balancing individual safety, needs, desires with personal respect for the rights desires of others
Our own comfort levels with talking about it…
Autism and DD

Individuals with DD may actually have better social skills and understanding of the complex “nuances” of social relationships than individuals with Autism, who may have higher cognitive levels but less social competency.....
COGNITIVE ABILITY IS NOT AN INDICATOR OF SOCIAL SKILLS PROFICIENCY

Higher functioning students are often perceived as having better social communication skills than they really do. (i.e. – “He should know better!”)
Common Stereotypes of People with DD regarding sex:

- Individuals w/ DD are forever childlike in nature; sexual interest won’t develop
- They are unable to understand their sexual desires
- They are asexual or uninterested in sex
- Their sexual behaviors are uncontrollable; they are hypersexual
- Sex education will only 'give them ideas'

(Lennox, 2008)
What Do We Know About Teens with DD and Sex?

Previously held beliefs that individuals with DD lacked sexual desire/drive (DeMeyer, 1974), are inaccurate. The majority of young adults with DD (as many as 75% by some reports) report sexual interest and/or engage in sexual behaviors (Haracopos & Pedersen, 1992; Hellermans et al, 2007; Van Bourgondian, 1997).

...People are people, and most all people have sexual feelings and emotions, including those with DD.
What Do We Know About Teens with DD and Sex?

There is a significant difference between individuals with DD who report an interest in having intimate relationships with others, and the number of those that attain a close mutual relationship (sex and/or marriage) (Stokes & Kauer, 2005; Haracopos & Pedersen, 1992)
What Do We Know About Teens with DD and Sex?

Many individuals with DD do not receive sufficient sex education: either in the form of developing relationships or fact-based information about the human body and appropriate sexual behavior (Cromer, et al, 1993, Silber & Batshaw, 2004)...

... Where does this disconnect lead??
What Do We Know About Teens with DD and Sex?

Individuals with DD are at 4 to 10 times higher risk for victimization (Sorenson, 2002)

Individuals with DD do tend to engage in inappropriate public sexual behaviors compared to their non-DD peers

- touching private parts in public
- disrobing in public

Reports as high as 90% of individuals with DD have engaged in some form of unsolicited sexual behavior toward another person including staring, touching, or explicit language (Haracopos & Pedersen, 1993)
What Do We Know About Teens with DD and Sex?

Teens and adults with DD are more likely to focus their exploration or romantic interests on “mismatched” others: people very familiar (family/caretakers, teachers), or unfamiliar people (strangers, celebrities). They also tend to pursue romantic targets for longer lengths of time than neurotypical peers.

Such behaviors put people with DD at risk for legal intervention related to perceptions of stalking, harassment or “assault” types of allegations.
What Do We Know About Parents of Teens with DD?

Parents worry that their child’s behavior will be misinterpreted by others as “knowingly” sexually inappropriate.

Parents worry about their child’s risk for victimization.

Parents are reluctant to address sex education with their children with DD, but at the same time they are concerned about what their teens think and do about sex.

(Ruble & Dalyrymple, 1993; Koller, 2000; Sgro & Pinto-Martin, 2005)
Teens with DD and Sex

- Physical Drive / Sexual Interest
- Level of Social Competence / Understanding
- Access to Info. and Education

High

Low
Reasons We Need to Teach Human Sexuality to Individuals with DD...

Many individuals with DD don’t have even basic knowledge about sexuality and the human body.
Individuals with DD do not have natural place/persons from which to seek answers to natural curiosities and questions
   Exception = “the internet”….. (yikes!)

Individuals with DD have the same hormones, feelings and needs as peers

(Adapted from: Gerhardt, P. & Attthowe, M.; OAR, 2008)
Reasons We Need to Teach Human Sexuality to Individuals with DD...

Lack of knowledge + cognitive/social vulnerability = higher risk for abuse
Strong need to teach basic knowledge for self-protection and advocacy

Lower self-esteem and/or lack of understanding can lead to doing “anything to be accepted”
Lack of basic skills can lead to misunderstandings about what is healthy vs. unhealthy sexual behaviors by self or others
(Adapted from: Gerhardt, P. & Attthowe, M.; OAR, 2008)
And Most of All…

Because people with developmental disabilities and autism are People First, and they have a right to learn about their bodies and information that will allow them to become sexually healthy persons

(Adapted from: Gerhardt, P. & Attthowe, M.; OAR, 2008)
The Good News is…

People with DD that receive sexual education are more likely to engage in more appropriate sexual behaviors than peers who do not. (Van Bourgondian et al, 1997)

In other words….

We Can Teach!
When (do we bring it up) Where (does instruction occur), and What (do we teach) ??

It is normal to worry about when to bring it up, and exactly what to say… Parents and teachers worry about “putting ideas in his/her head”, or overshooting what topics to discuss…

“Did you hear the one about”…..?
Sex Education and DD

Sexual education starts with understanding:

1. Basic facts about the human body and how it works
2. Knowledge about when/where/how it is OK to explore your own sexual/physical feelings
3. Underlying social skills involved in developing friendships and intimate relationships with others.
When (do we bring it up): Things to Consider

Individuals with DD may differ in the rate of their physical vs. developmental maturation…

Physically, puberty can happen as early as 9-10

Most individuals with DD should have some direct instruction about their body and how to approach self-exploration by early teens, when bodies are changing rapidly (onset of menstruation, nocturnal emissions, etc.)

If you notice changes in behavior (disrobing at inappropriate times)

Ideally, instruction should be proactive and before unhealthy or concerning behavior is exhibited
The 5-year Rule…

When considering what to address, think about what will be relevant to the person in the next 5 years, as a metric for what to teach.
Where (does instruction occur):

Home-School Connection

Sex education should be a collaboration between parents and school professionals
Frank discussions are necessary to ensure clarity around what to teach, and how to do it
You must decide individually where to best address education: home-school connection is key
What (do we say): Things to Consider

Physical development:
Regardless of age, boys and girls need to understand their changing bodies, even if those changes come earlier than we would prefer

• How scary is the concept of menstruation if you don’t know what it is?

Developmental age:
Basic instruction around the human body, and rules about touching (others as well as others touching you) may be appropriate, even with older individuals
Keep in Mind…

While “we” (family, teachers, caregivers) tend to view individuals with ASD’s and DD in our lives from a developmental perspective, the world-at-large definitely perceives and judges behavior appropriate or not based on age-related standards and expectations.
The Basics: “The Facts of Life”

Human Body: Sometimes my body feels…. “Itchy”!
   - Tara, Age: 16

For Girls: Menstruation – it’s purpose and what to expect

Touch: When and Where
   Private vs. Public behaviors

Talk: What’s OK to Say and to Whom

Self-advocacy: “No – Go - Tell”
   When others try to talk to and/or touch you in an unwanted way
Visual Supports

Private body parts are the parts covered by the swimming suit

Private body parts are the parts that should be covered by the swimming suit
Visual Supports
And if it all weren’t awkward enough…

It’s important to talk about masturbation:
Teens with DD need to know it’s a natural and healthy human activity, and that it’s appropriate when one knows when and where it’s OK to do it (at home, in private)

www.sexualityandu.ca
Issues to Consider: Masturbation

It’s normal; self-exploration of the body begins very early in life.
It can be a healthy, normal sexual outlet.
It’s very likely going to happen whether we teach it or not; much better to teach guidelines and appropriate boundaries around when/where rather than risk the alternative.

Sexual behaviors in public tend to happen as a result of lack of instruction.
Things to Know: Masturbation

Designate where it’s OK
Really the only option is individual’s own bedroom

Avoid teaching in the bathroom

Teach rules around “time and place”
Sometimes it’s not an option

Schedule alone time into individual’s day, to help encourage appropriate “time and place” concept
Allow access to socially appropriate magazines (behaviors in public can also occur in attempt to locate visually stimulating triggers)
Dealing with Problems

Interrupt the behavior but don’t over-react or punish
Remind individual of the rules; develop visual supports if needed
Re-direct the student to an activity that conflicts with the behavior
  Requires use of hands, physical activity, requires intense focus, etc)

Reinforce individual when engaged in appropriate other behaviors
Dealing with Problems

Problem Solving… “Problems”
Is there a skill deficit, and if so what kind?

- Lack of information?
- Lack of social skill or contextual understanding?
- Failure to generalize a learned skill?

Understanding the Problem through the lens of “What is the skill deficit here?” is a much more effective approach than, “Everybody panic”!
Beyond the Basics

*Parents and team members will have to discuss and determine what level of “complexity” of sex education is appropriate for each individual in question.*

**Most Individuals**

- Basic information about the human female/male body, understanding personal feelings, and guidelines for exploring sexuality

**Many individuals**

- Development of romantic/intimate relationships
  - Does the person socially engage in some way?
Beyond the Basics

Developing close and intimate relationships with another requires a foundation in social skills that begin much earlier in life.

Dreams and Expectations: Building a Rationale

Social skills and interacting with others

- Sharing; Conversation skills; Knowing your own interests and sharing them with others; Taking an interest in others

Grooming and hygiene

- Understanding the connection between taking care of yourself and your hygiene and building relationships with others
Beyond the Basics

Putting dating and romance into context
People who are dating don’t “just engage in romance or sexual behaviors. They also:

- Go to movies
- Each lunch together at school and talk
- Hang out in groups with other friends
- Share common interests and participate in activities related to those interests
- Call each other on the phone
- Come over for dinner with each other’s family
- etc., etc.
Strategies for Instruction

Social Stories
  Enhance social understanding

Video Modeling
  Visual model of “what appropriate social skills look like”

Social Scripts and Narratives
Role Play
  Structured practice

Circle of Friends
Sometimes I have busy hands. When I get excited, I put my hands in my mouth or down my pants. This makes my hands dirty. I will try to have calm hands by holding my hands still. If I do this, then I will stay clean.
Public and Private

Public places are where other people see and talk with me. I see and talk to people at school, at the store, and at places like McDonalds.

Private places are where I can be alone. When I am in my bedroom or my bathroom at home, this is a private place.

When I want or need to do things like take my clothes off or touch myself in my private areas, I need to be in a private place, like my bedroom at home or my bathroom at home.

In public, like at school or the store, I need to keep my clothes on. This is not the place to touch my own or others’ private areas.

I will wait to take my clothes off or to touch myself until I am alone and in a private place.
In an effort to show appreciation for those people in the community who have shown exemplary bus riding skills, the mayor today called for a city wide “Thanks to Our Transportation Partners” Day. Bus drivers all over the region were asked what qualities make for a great bus rider, and the vast majority responded that they valued customers who show up on time for the scheduled bus stop, and have their money ready, with correct change. They indicated that this went a long way in keeping them on time for their daily stops, which is very important for getting people where they need to be on time.

Drivers also indicated that riders who enter the bus quietly and who use good hygiene are greatly appreciated. “It’s not fun to ride on a crowded bus with someone who doesn’t shower or use deodorant”, said Tom Higgins, a 20-year veteran of the Transportation Unit. “Cleanliness may not seem necessary to ride a bus, but it is an important part of being a member of a community”, he went on to say. The final characteristic that bus drivers agreed make an exceptional rider was using a quiet voice. All stated that when a rider talks loudly to himself or to others, it can make other riders upset and nervous, and it can really give the drivers a headache!

The city thanks all considerate bus riders.
Are these places public or private?
Graphic Organizers

Things Friends Do

Go places together

Talk to Each other

Share; compromise

Treat each Other w/ respect
Circle of Friends

Family and Friends
- touching
- marriage
- sex
- hug
- talk on phone
- "hanging out"
- "small talk"
- movies
- "say hi"
- ask the time

Acquaintances
- kiss on cheeks
- "hanging out"
- "say hi"
- "small talk"
Repeat, repeat and repeat again
People with DD, as with other skill development, may require multiple discussions

Stay concrete with your examples
Abstract information can be challenging; use visuals and keep it concrete

Don’t overload with information
This is an issue that will likely require multiple sessions to cover topics; though admittedly awkward, don’t try to do this in “one fell swoop”
A Few References

Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality. Terri Couwenhoven


The Facts of Life...and More: Sexuality and Intimacy for People with Intellectual Disabilities

Autism-Asperger's & Sexuality: Puberty and Beyond. Jerry & Mary Newport