Sexuality Education for Children and Adolescents with Autism Spectrum Disorders

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Objectives

Participants will be able to answer:

- What is sexuality education?
- Why is it important for children and teens with ASD?
- What does the research say?
- What information should be covered?
- What tools can I use to teach this information?
- What about inappropriate sexual behaviors?
- How can I decrease vulnerability in my child/clients with ASDs?
What people think when they hear “sexuality education”:

- “Sex ed”
- Intercourse
- Sexually transmitted illnesses (STIs)
- Embarrassment/shame
- Anxiety
Sexuality Education is NOT all about sex!

“Sexuality education is a life-long process that encompasses many things: the biological, socio-cultural, psychological and spiritual dimensions of sexuality.” (Gerhardt)
If it’s not all about sex...what IS it?

- Identity
- Safety
- Love
- Intimacy
- Relationships (sexual and nonsexual)
- Positive, adaptive behaviors
- Increase self-understanding, self-esteem, and self-determination
- Replace inappropriate behaviors with appropriate, pro-social behaviors

Hartman, 2014
Goals of Sexuality Education (Gerhardt)

Comprehensive Sexuality Education

Accurate Information
- Masturbation
- Abuse
- Development
- Puberty
- Sexual orientation

Personal Values
- Responsibility
- Self-esteem
- Right vs. wrong
- Reality vs. fantasy
- Respect
- Limits

Social Competence
- Decision making
- Personal advocacy
- Refusal skills
- Dating
- Avoidance of dangerous situations
Topics covered in sexuality education

- **Body awareness**
  - Body parts, names, and functions
  - Okay and not okay touch
  - Who/how/when to report
  - Necessity of examinations – from who and how
  - STIs
  - Abstinence and safe sex
  - Symptoms indicating need for treatment

- **Social skills**
  - Greetings/eye contact/play skills
  - Sharing interests
  - Love and intimacy
  - Dealing with rejection

(Travers & Tincani, 2010)
Topics, cont.

- Romantic relationships and intimacy
  - Dating
  - Nonverbal cues
  - Listening skills
  - Consent
- Masturbation and meeting social norms
- Reproductive and parenting rights
  - Contraception

(Travers & Tincani, 2010)
Why is sexuality education important?

People with ASDs:

- Have the right to learn about relationships, marriage, parenthood, and appropriate sexuality
- Are unable to obtain information from environment without instruction
- Have normal sexual feelings
- Try to fulfill/express feelings in socially inappropriate ways

(Hartman, 2014; Travers & Tincani, 2010)
Why is sexuality education important?

Sexuality education:
- increases proper hygiene skills and health
- decreases instances of unwanted pregnancy, STIs, etc
- is not harmful
- more information leads to increased confidence and ability to make safe, healthy decisions

(Hartman, 2014; Travers & Tincani, 2010)
But...why do we need to teach this?

People tend to believe that...

- People with disabilities are asexual.
- People with disabilities are hypersexual.
- People with disabilities are all heterosexual.
- People with disabilities are sexually immature.
Problems accessing sexuality education

- Lack of research
- Not socially rewarded
- Fewer friendships
- Attend different schools
- Gender ratio
- Communication
- Literacy and interpretation challenges
- Less privacy and independence
- Sensory sensitivities

(Hartman, 2014; Travers & Tincani, 2010)
Type and sources of information

- Lower levels of sexual knowledge
- Less knowledge of privacy issues related to sexual behavior
- Receive less information about sexuality from peers
- Less able to define sexual activities than IQ matched peers with developmental delay
- Males have high levels of *perceived* knowledge (particularly around condom use), but low levels of *actual* knowledge
- More likely to report television and “making mistakes” as sources of knowledge
- Less likely to report social sources (parents, teachers, peers) as sources of knowledge
“Why talk about sex with him when it will most likely never happen? It is cruel to get his hopes up.”

Lack of information, support, and strategies

Parents WANT support

Focus on abuse and hygiene, rather than the full spectrum of sexual and reproductive health

Do not generally believe their children can have appropriate sexual behavior and/or a future where they can be appropriately sexually active

(Ballan, 2012)
Parent Perspectives

- Challenges in discussing sexuality
  - Comprehension
  - Children don’t initiate the conversation
  - Over-generalization
  - Discernment
  - Stereotypic and repetitive behaviors

(Ballan, 2012)
Parent Perspectives

- Lack of support
  - Feelings of isolation
  - Difficulty accessing information from professionals
    - only address when it is a behavioral problem
  - Lack of information regarding normative behavior
Parents are concerned about:

- Misperceptions of children’s behaviors
  - Non-sexual behaviors interpreted as sexual (sensory/social)
  - Sexual expression mistaken as deviant (hugging)
  - Normative sexual behaviors are stigmatized and feared (masturbation, puberty)

(Ballan, 2012)
What professionals of children with ASD think:

- Parents will have the conversation.
- Schools will have the conversation.
- I’ll address it when/if it becomes a problem
- Lack of training
“When people with disabilities are denied access to sex education, they become perfect victims because they can’t report what they can’t say.”

(Hingsburger)

- Communication and social deficits
- Desire to be accepted
- Overprotection
- Lack of sexuality education
- Vulnerable to accusations of harassment, stalking, or abuse

(Hartman, 2014; Travers & Tincani, 2010)
Vulnerability

- Sexuality education serves *preventative* function
- If people know what is healthy and good, they will be able to discriminate what is bad and wrong
- Sexuality education decreases and prevents instances of maladaptive, inappropriate, and dangerous behaviors

(Hartman, 2014; Travers & Tincani, 2010)
Vulnerability and Victimization

- People with ASD may have difficulty:
  - identifying “safe” and “unsafe” behaviors
  - understanding others’ negative intentions
  - asserting own wishes and intentions
- 78% of adults with ASD reported at least one occurrence of victimization
- 2-3 times more likely to be abused

(Brown-Lavoie, Viecilli, & Weiss, 2014)
Language matters!

- Language used is framed in deviancy and fear
  - Should be framed from a “problem-based” or “deficit-based” perspective
- Words such as “stalking” or “obsession” create fear
  - May be more accurate that the behavior is resulting from lack of experience, social deficits, or immaturity

(Hartman, 2014)
What Should Children Know?

When Should They Know It?

—Today—
in Room 301—
"The Birds and The Bees"
(And much much more!)
## What’s “normal”?  

<table>
<thead>
<tr>
<th>Age</th>
<th>Typical Behaviors</th>
</tr>
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<tbody>
<tr>
<td>Birth to 2 years</td>
<td></td>
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</table>
|               | Discovering body  
|               | Touching genitals for pleasure                                                   |
| 2-5 years    |  
|               | Exploration and curiosity about body and genitals  
|               | Dressing up (including boys dressing up as girls)  
|               | Questioning about how babies are made  
|               | Joking about genitalia and body functions  
|               | Some reflexive sexual responses                                                   |
| 5-10 years   |  
|               | Masturbation for pleasure  
|               | Continued curiosity about bodies                                                  |
| 10-14 years  |  
|               | Continued exploration with same and opposite sex peers  
|               | Sexual fantasies  
|               | “Boyfriends” and “girlfriends;” dating, kissing  
|               | Masturbation to orgasm                                                            |
| 14-18        |  
|               | Becoming self-conscious  
|               | May begin having sex, sexual wishes and fantasies  
|               | Masturbation for pleasure                                                          |
What should be taught?

- **Gender**
  - Boys vs girls
  - Slang words for both sexes
- **Body parts and fluids**
  - Basic body parts
  - Bodily functions
  - Internal body parts (including reproductive organs)
- **Growing and changing**
  - What do “normal” bodies look like?
  - Changes in self-care tasks
What should be taught?

- Puberty
  - Changes in self-care
  - Menstruation
- Appearance and personal hygiene
  - Clean vs dirty; tooth care; hair care; showering; washing hands
  - Fashion; personal style; make-up
- Public vs. private
- Sexual health
- Sensory sensitivities
- Relationships
- Self-advocacy and self-awareness
What should be taught?

- Dating, intimate relationships, and sex
  - Attraction, flirting, readiness
  - Dating rules, planning, skills, safety
  - Online dating, phone/email skills, relationship skills
  - Ending relationships, relationship stages
  - Characteristics of healthy/unhealthy relationships
  - Disclosure of diagnosis
  - Consent
  - Stages of intimacy
  - Sexual intercourse
  - Contraception
  - Stalking, sexual intimidation, and harassment
Masturbation

• Should only be considered a problem if it is:
  ○ In public
  ○ Excessive (causing pain, interfering with other daily activities)
  ○ It is causing other behavioral issues
  ○ The child is finding it upsetting

• Teach privacy (i.e. private bedroom)
• Have a term the child is able to use and understand (“private time,” “private touching,” etc)
• Supplement with visuals as necessary
• Teach hygiene
Reducing vulnerability

- **Safety skills considerations**
  - “Prison of Protection” vs. “Ring of Safety” (Hingsberger)
  - “Stranger Danger”
  - “Good Touch/Bad Touch”
Reducing vulnerability

*What should be taught?*
- Assertiveness
- Consent
- Bullying and cyber-bullying
- Surprises, privacy, and secrets
- Sexual harassment
- Stalking
- Sexual abuse
- Rape
- Abuse within relationships
- Safety when answering the door/phone
- Safe dating (online dating)
- Internet safety
- Prostitution
- Child pornography
Internet safety

- Nothing is private!
- Recognizing credible websites
- Do not share information online that you would not share with a stranger
- Rules for meeting up with online friends
- Cyber-bullying

- Online stalking
- Appropriate behavior
- Texting skills
- Unsafe support groups
- Sexting
- Pornography
How should things be taught?

- Visuals
- Concrete rules
- Task analysis
- Video modeling and video self-modeling
- Use reinforcement
- Social stories
- Social scripts
- Role-play
Visuals

Stages of an Intimate Relationship
Task Analysis

Changing My Pad

Go to bathroom.

Close door.

Pull down underwear.

Put new pad on underwear.

Pull up underwear.

Put old pad in the wastebasket.

Take off old pad.

Wash hands.
Social Stories: Asking For and Having Private Time
Concrete rules: Talking to strangers
Social Stories: My Body Book and Touching Rules
Things to avoid

- Euphemisms
- Unclear language or rules
- Assumptions about what a child knows or does not know
- Teaching beyond the child’s developmental level
Why might inappropriate sexual behaviors occur?

- Difficulties understanding social rules
- Difficulties with communication
- Learned behaviors
Why might sexual behaviors occur?

- Sensory issues, medical issues, pain/discomfort
- Medication
- Boredom
- Seeking attention
- Inability to masturbate effectively
- No opportunity to express appropriately
When problem behaviors occur...

- Does the behavior need to be changed?
- Define the behavior that is problematic
- Functional Behavior Assessment

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<tr>
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<th>Consequence</th>
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<tbody>
<tr>
<td>What happened before the behavior?</td>
<td>Clearly defined behavior</td>
<td>What happened after the behavior occurred?</td>
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### Examples

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| John is a 13 year old, nonverbal male with an autism spectrum disorder. John is working with his aide on a sorting task. | John gets an erection. He continues to work on the sorting task, but periodically vocalizes, tugs at his pants, or hits his genitals. | • Is this normal or abnormal?  
• Why is this behavior occurring?  
• What should the consequence be?  
• Is this a problem behavior?  
• What should be done to manage this in the future? |
Sarah is a 12 year old girl with autism. She goes to a friend’s house to play for the afternoon. Sarah comes home from her friend’s house with temporary tattoos on her breasts, inner thighs, and bottom. She tells her mother that her friend suggested it would be fun to put tattoos on their private areas. When asked if she thought it was a good idea, Sarah says, “I really like playing with Anna.”

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| Mark is an 11 year old boy with Asperger’s Syndrome. He was watching YouTube videos and stumbled upon a comedy sketch involving sexually explicit language and visuals that were both inappropriate and unrealistic. | Mark talks about what happened in the sketch and perseverates on the language he heard in the video. He repeatedly asks his mother if the word “penis” is a bad word, and if he would get suspended for saying it at school. He asks other kids if they have seen the video and explains its content. He asks familiar and unfamiliar adults if they have heard about the video, and asks if they think it is funny. | • Is this normal or abnormal?  
• Why is this behavior occurring?  
• Is this a problem behavior?  
• What should the consequence be?  
• What should be done to manage this in the future? |
Evelyn is a 10 year old girl with autism who is in a self-contained classroom. Evelyn is given a task to complete, and prompted by her teacher to “finish her work.”

Evelyn stands up from her chair and presses or rocks her genitals against items in the classroom. When prompted, Evelyn will sit back down, but will stand up again as soon as her teacher’s back is turned.

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| Javier is a 16 year old boy with Asperger’s Syndrome. He has recently decided that he would like to have a girlfriend, and is attracted to a girl in his math class. | Javier sends the girl 15 text messages over the next two days. He knows that he should not pressure a girl into doing something she does not want to do, so he writes, “Do you want to be my girlfriend? You can choose, because I’m not pressuring you. I would like to go on dates with you and kiss you and be your boyfriend.” | • Is this normal or abnormal?  
• Why is this behavior occurring?  
• Is this a problem behavior?  
• What should the consequence be?  
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Resources

References