Approach to Puberty and Sexual Education in Adolescents with Developmental Disabilities

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Goals

• Appreciate the *Who, What, When, Where, How, and Why* Puberty and Sexuality Education is needed for Children and Youth with Special Health Care Needs (CYSHCN).
Objectives

- Identify 1 possible unintended bias through reflection.
- Identify at least 1 environment in which CYSHCN and their caregivers can access Puberty and Sexuality Education through presented material.
- Understand at least 1 difference each teaching environment may contribute to learning about Puberty and Sexuality Education through presented material and reflection.
- Identify at least 1 curriculum, book, and/or online available resource which may provide information regarding Puberty and/or Sexuality Education provided at the end of presentation.
Agenda

- Reflection
- 4 Learning environments
- Scenario
- Discussion: Differences in learning environments
- Reflection
- Resources
- Close
Please Grab Your Smart Phone

- Please go to kahoot.it

Once ready please:
- Enter the game PIN
- Create a nickname
- Push ok, go
- Then match the pattern
- Answer questions as they come
Reflection: Approaching Puberty

• Take a moment and reflect on the following:
  • Who did you talk to?
  • What did you talk about?
  • When did you first gain access to the information?
  • Where did you go to get information you needed or where did the information get to you?
  • How did you feel about the information?
  • Why was getting the information so important?
  • What were your thoughts about a person with disabilities regarding puberty and sexual health at that time?
4 Possible learning environments of puberty and sexuality education

- Doctor’s office
- School
- Home
- BCBA/therapist/other provider’s office

- Where else?
- What are the differences?
Scenario: Monday Morning Meeting with the Doctor

• 9 year old Matthew presents for his annual well child examination. He has a history of ASD, ADHD and Asthma.

• 12 year old Abigail is new to the state. She has ASD and Anxiety Disorder. Parents are very concerned about worsening behaviors associated with her periods.

• Kayla is a 18 year old with history of CP associated with scoliosis, seizure disorder, and moderate Intellectual Disability. Kayla recently disclosed to her mother she had sex with her boyfriend 6 months ago.
Share Your Thoughts

• When in childhood should the topic of puberty and sexuality be raised in this population?
• Should the topic of puberty and sexuality be raised during any of these encounters? Why or why not?
• Who is responsible for raising issue of sexual health and puberty?
• What are the topics that should be discussed?
• What barriers can you identify when raising this topic?
• How do you define sexual health, sexuality, puberty? Who is a sexual being?
Learning environment: Medical Home

- A Medical Home is an **approach** to providing high quality and cost effective health care rather than a structure or health care complex.
Learning environment: Medical Home

Family Centered
Continuous.
Comprehensive
Accessible
Coordinated
Compassionate
Culturally Competent
Quick Definition: Children and Youth with Special Health Care Needs (CYSHCN)

Those children who have or at risk for chronic physical, developmental, behavioral, or emotional conditions who require health related services of a type or amount beyond that required by children generally.

-The Federal Maternal and Child Health Bureau, 1997
Why Discuss Puberty and Sexuality Education in the Medical Home?

- Puberty and Sexuality is Normal
- Help to obtain a life with more personal fulfillment
- Independence
- Every person is a sexual being

Sexuality of Children and Adolescents With Developmental Disabilities, Pediatrics, July 2006, Volume 118/Issue 1
Why Discuss Puberty and Sexuality Education in the Medical Home?

• Protection- Adolescents with disabilities are likely more vulnerable to sexual assault
  – Decreased ability to flee or fight off an attacker
  – An expectation of increased compliance
  – Increased tolerance of physical intrusion
  – Deficits in communication skills
  – Inability to implement effective safeguards

Care of the Adolescent After an Acute Sexual Assault, Pediatrics, March 2017, Volume 139/Issue 3
Why Discuss Puberty and Sexuality Education in the Medical Home?

• Inform & Empower- Factors that influence whether people with disabilities report sexual assault:
  – understanding and the significance the victim attaches to the incident
  – ability to communicate what happened
  – level of trust or expectation of being believed and feeling safe

Care of the Adolescent After an Acute Sexual Assault, Pediatrics, March 2017, Volume 139/Issue 3
How is Puberty and Sexuality Education Done in the Medical Home?

• Discuss issues of physical development, maturity, and sexuality on a regular basis, starting during early childhood and continuing through the adolescent years.
• Use appropriate vocabulary when labeling genitals.
• Ensure the privacy of each child and adolescent.
• Assist parents in understanding how cognitive abilities of their children affect behavior and socialization.
How is Puberty and Sexuality Education Done in the Medical Home?

• Be aware of special medical needs, such as modified gynecologic examinations, latex-free protection from STI and unplanned pregnancies, and genetic counseling when appropriate
• Recognize that CYSHCN are at increased risk of sexual abuse and monitor for early indications of abuse
• Routinely ask about history of sexual violence, dating violence, and sexual assault
• Provide appropriate routine STI screening
How is Puberty and Sexuality Education Done in the Medical Home?

- Encourage CYSHCN and their parents to optimize independence, particularly related to self care and social skills
- Advocate for developmentally appropriate sexuality education in home, community, and school settings
- Provide families information regarding appropriate community programs, books, internet resources that address issues of sexuality for YSHCN
What should CYSHCN be taught about Puberty and Sexuality Education?

• The correct names for body parts
• Personal hygiene
• How to express physical affection in a manner that is appropriate to their apparent ages
• Discourage inappropriate displays of affection
• Expectations that their behavior conforms with family and societal standards for privacy and modesty
What should CYSHCN be taught about Puberty and Sexuality Education?

• The difference between acceptable private vs. public behaviors

• The right to refuse to be touched at any time

• No secrets from their parents about having been touched inappropriately
Helpful questions: What to ask a PCP
Scenario: Monday Morning Behaviors in the Waiting Room

• 6 year old Grayson has been leaning against the edge of tables and pushing objects and toys against his genitals at school. The teachers have expressed their concern to his caregivers.

• 9 year old Allison is bored in the waiting room and her mom keeps saying, “Take your hand out of your pants”.

• 13 year old Tim is new to the office. He is a super friendly and is willing to give every person entering the office a hug. Dad feels uncomfortable when Tim hugs adult strangers or small children.
Learning environment: Board Certified Behavior Analyst (BCBA) in the clinic, home, or in the community

- Assist caregivers and person’s diagnosed with Autism Spectrum Disorder (ASD)
- Develop programs individualized to the learner using Applied Behavior Analysis (ABA)
- Assist in creating learning opportunities to promote positive behaviors and the reduction of problem behaviors
BCBA: Approach to Puberty and Sexual Health

• Assess current learning abilities
• Identify parental concerns, child concerns, and social concerns
• Develop programs to assist understanding of: Public vs private, reporting, nakedness, hygiene, body parts, appropriate touch, and more
• Address issues when children are engaging in developmentally normal behavior in a socially unacceptable place
Helpful questions: What to ask a BCBA

Questions
- What questions would you ask a BCBA?

What to look for
- Open communication
Our Expectations During Demands

• What do we expect when we say:
  • “Change your clothes?”
    – Socks
    – Shoes
    – Pants
    – Underwear
    – Bra
    – Shirt
    – Belt
    – Coat
  • “Brush your teeth?”
    – Toothpaste
    – Toothbrush
Our expectations during demands

• What do we expect when we tell someone to:
  – “I think you need to shave.”
  – “Have you changed your pad recently?”

*How many steps are in these activities?
Break it down: Pad Changing-Start to Finish

Easy you say? Just 30+ simple steps:

1. Identifying the sensation/need to change a pad
2. The ability to ask to go to the bathroom
3. Getting to the bathroom/Opening door
4. Turning on the light
5. Closing the door
6. Making sure the toilet seat is in the correct position
7. Unbuttoning/unzipping pants
8. Pulling down pants and underpants
9. Removing soiled pad
10. Disposing of soiled pad (rolling, wrapping, throwing in trash)
11. Accessing clean pad
12. Opening clean pad
13. Throwing wrapper in trash
14. Removing sticker
15. Throwing sticker in trash
16. Lining up pad with underwear,
17. Attaching the pad (wings too)
18. Pulling up underwear
19. Pulling up pants
20. Snapping and zipping (adjusting)
21. Flushing
22. Getting to sink
23. Turning on water
24. Rinsing hands
25. Getting soap,
26. Rinsing hands
27. Turning off water
28. Drying hands
29. Turn off light
30. Opening door and leaving restroom
Learning environments: School

What do kids learn about sexuality education and puberty at school?

- Depends on:
  - What state you live in
  - What school district
  - What curriculum is used

- Did you know:
  - Most government funded sexual health programs are abstinence only
  - Sexual health does not have to be taught in schools

SEVEN ESSENTIAL COMPONENTS OF K-12 SEXUALITY EDUCATION

- Anatomy and Physiology
- Puberty and Adolescent Development
- Identity
- Pregnancy and Reproduction
- STDs and HIV
- Healthy Relationships
- Personal Safety

GRADE GROUPINGS: K-2, 3-5, 6-8, 9-12

Helpful questions: What to ask schools

- What sexual health curriculum are you using?
- What does the special needs sexual health curriculum look like?
- When does your school begin implementing sexual health education?
- What protocols do you have in place when a child engages in developmentally normal behaviors that occur in a socially unacceptable place?
- How is your facility able to support my child throughout their development and normal sexual health development?
Definitions: What does all of this mean?

Sexuality

• The World Health Organization defines sexual health as 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 violent.

http://www.cdc.gov/sexualhealth/
Definitions: What does all of this mean?

Puberty

• *Puberty is a normal phase of development that occurs when a child's body transitions into an adult body and readies for the possibilities of reproduction.*

http://tweenparenting.about.com/od/physicalemotionalgrowth/g/Puberty.htm
Who is a sexual being?

• “...All beings from birth until death are sexual beings...”

Youthembassy.com/parents_sexuality.asp

• “Even today, many people refuse to acknowledge that all people have sexual feelings, needs, and desires, regardless of their physical and/or mental abilities. As a result, many young people who live with disabilities do not receive sex education, either in school or at home.”

**Definitions: What does all of this mean?**

- **Unintentional bias**

  [http://opi.mi.gov/users/dougdoty/weblog/12222/Sex_Education_for_Physically_Emotionally_and_Mentally_Challenged_Youth.html](http://opi.mi.gov/users/dougdoty/weblog/12222/Sex_Education_for_Physically_Emotionally_and_Mentally_Challenged_Youth.html)

<table>
<thead>
<tr>
<th>Myths</th>
<th>Facts</th>
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<tbody>
<tr>
<td>People with disabilities are not sexual</td>
<td>All people—including young people—are sexual beings, regardless of whether or not they live with physical, mental, or emotional disabilities</td>
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<tr>
<td>People with disabilities are childlike and dependent</td>
<td>Societal discomfort—both with sexuality and also with the sexuality of people who live with disabilities—may mean that it is easier to view anyone who lives with disabilities as an ‘eternal child.’ This demeaning view ignores the need to acknowledge the young person’s sexuality and also denies her/his full humanity.</td>
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<td>People with disabilities cannot control their sexuality</td>
<td>This myth spins off the other two—if people with disabilities are neither asexual nor child-like, then they perhaps they are ‘oversexed’ and have ‘uncontrollable urges’. Belief in this myth can result in a reluctance to provide sex education for youth with disabilities. The reality is that education and training are key to promoting healthy and mutually respectful behavior, regardless of the young person’s abilities</td>
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How have your thoughts changed

• Should the topic of puberty and sexuality be raised during any of these encounters? Why or why not?
• Who is responsible for raising this issue?
• What are the topics that should be discussed?
• When in childhood should the topic of puberty and sexuality be raised in this population?
• Are there barriers to raising this topic?
Resources: Social Stories

- Boys, Girls and Body Science by Meg Hickling
- What’s Happening To Me? by Peter Mayle
- Special Boys’ Business by Heather Anderson, Fay Angelo and Rose Stewart
- Puberty and Special Girls by Heather Anderson, Fay Angelo and Rose Stewart
Resources: Books

Girls

• The Body Book: It’s A God Thing! by Nancy N. Rue
• Ready, Set, Grow!: A What’s Happening to My Body? Book for Younger Girls by Lynda Madaras and Linda Davick
• The Care & Keeping of You: The Body Book for Girls (American Girl Library) by Valorie Schaefer and Norm Bendell

Boys

• On Your Mark, Get Set, Grow!: A “What’s Happening to My Body?” Book for Younger Boys by Lynda Madaras
• The Guy Book: An Owner’s Manual by Mavis Jukes
Resources: Online

- http://www.advocatesforyouth.org/
- http://www.siecus.org/
- Youthembassy.com/parents_sexuality.asp