Sexual Education and Sexual Assault Prevention for Adolescents with Disabilities

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Learning Objectives
At the conclusion of this presentation, participants should be able to:
1. Describe multiple modalities (books, websites, pamphlets, pictures, anatomically correct dolls) used for sexual education for adolescents with disabilities
2. Outline the risk for sexual assault in adolescents with disabilities and how to screen for abuse
3. Discuss current literature on prevention of sexual assault and describe some educational programs to teach adolescents with disabilities to avoid assault

Disclosure
- Dr Quint and Dr Ernst and their families have no disclosures for this presentation
Themes

• Teenagers and women with special needs are vulnerable
  – To abuse and exploitation
  – To not being able/allowed to express feelings

• As Adolescent Reproductive Health providers:
  – Great opportunity to help teens and families with the adolescent transition
  – Today focus on
    • Education
    • Abuse prevention

2012 Statistics

• Ages 5-20
  – 5.4% have a disability (girls around 4%)
  – 4% have a cognitive disability
• Most increased in recent years: ADHD/autism


Why is Adolescence so challenging?

• Adolescence = Turbulence
• For teens
  – Adolescence itself
  – Dealing with periods
  – Realizing they are different
  – Friendships are hard
  – May lack knowledge/skills for safe sex
  – Past sexual abuse may impact sexual expression

Greydanus DE, Pratt HD, Patel DR. Dis Mon. 2012 May;58(5):258-320
Why is Adolescence so challenging?

- Adolescence = Turbulence
- For parents: one more thing to worry about
  - Start of growing up
  - Dealing with periods
    - Anticipatory guidance
  - Sexuality and fertility
    - Often considered asexual
    - Concerns about safety
  - Living situation at home
  - Privacy issues


Sexual education for teens with disabilities

- Sexual education in all teens
  - Parents
  - Peers-experience and talking
  - School-based education
  - Social media
- For teens with disabilities
  - Peers interaction are more limited
  - School education may not include them
  - Families may shield them from information
  - Some info from social media-biased-quality?


Healthy Sexual development in teens with disabilities

- Knowledge
- Opportunity for peer interactions
- Relationships and exploration
- Safety from abuse
Sexual knowledge in teens with ID

- 60 teens (16-21): 30 with mild ID, 30 peers
- Tested sexual knowledge
- Results:
  - Overall teens with ID had lower knowledge
  - Women more knowledge in control group
  - Men with ID more knowledgeable than women with ID


Sexuality Perceptions of mothers of kids with ID

- Spoke about fewer sexual topics in less detail
- Discussed sexual matters at a later age
- Were more cautious in their attitudes toward sexuality
- Reported having fewer sources of support
- Were more concerned regarding exploitation and abuse

Sources:

Sexuality in Adolescent Girls With and Without Physical Disabilities

<table>
<thead>
<tr>
<th>Girls’ Experiences at Age 16 by Physical Disability Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Disability Status</td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
<tr>
<td>No disability</td>
</tr>
<tr>
<td>Minimal disability</td>
</tr>
<tr>
<td>Mild disability</td>
</tr>
<tr>
<td>Severe disability</td>
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</table>

### Sexuality in Adolescent Girls With and Without Physical Disabilities

**Girls’ Experiences at Age 16 by Physical Disability Status**

<table>
<thead>
<tr>
<th>Physical Disability Status</th>
<th>Ever Had Sex</th>
<th>Been Forced</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disability</td>
<td>33.7%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Minimal disability</td>
<td>51.8%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Mild disability</td>
<td>36.3%</td>
<td>12.9%</td>
</tr>
<tr>
<td>Severe disability</td>
<td>42.1%</td>
<td>11.1%</td>
</tr>
</tbody>
</table>


### Substance Use by Adolescents with Disabilities, Ages 18-21

<table>
<thead>
<tr>
<th>Substance</th>
<th>General population</th>
<th>Teens with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol Use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>44%</td>
<td>54%</td>
</tr>
<tr>
<td>&gt; 2 Drinks in past 30 days</td>
<td>35%</td>
<td>22%</td>
</tr>
<tr>
<td>Illegal Drug Use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marijuana use</td>
<td>27%</td>
<td>16%</td>
</tr>
<tr>
<td>Any drug use</td>
<td>28%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Source: Yu, 2008

### Patient Presentation

- 15 year old patient with ID comes in for irregular periods
- She is mildly disabled, can communicate, reads at a third grade level
- She lives with parents
- Goes to regular school; 9th grade with special classrooms
  - No sex ed at her level
- Mom: "I just tell her that boys should never touch you"
Sexual Education

Most important things for the Provider to do:
- Bring up the topic
  - Confidential interview
- Acknowledge the family’s concerns and values
- Help families educate their daughters
- AAP and CPS have specific recommendations
  - Encourage dialog with families
  - Ask about sexuality and behaviors
  - Monitor for abuse

Pinzon j et al; Paediatr Chil Health 2006; 11: 43-8

Sex Education

Assess knowledge and safety

Assess ability to consent

Give age and development level appropriate education
Sex Education
Assess knowledge and safety
• Her terminology for body parts
• Her knowledge of reproductive anatomy and function

Anatomic Knowledge of girls with mild ID

<table>
<thead>
<tr>
<th></th>
<th>Known(%)</th>
<th>Unknown(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uterus</td>
<td>90.9</td>
<td>9.1</td>
</tr>
<tr>
<td>Testis</td>
<td>68.2</td>
<td>31.8</td>
</tr>
<tr>
<td>Tubes</td>
<td>54.4</td>
<td>45.6</td>
</tr>
<tr>
<td>Ovary</td>
<td>68.2</td>
<td>31.8</td>
</tr>
<tr>
<td>Vagina</td>
<td>50.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Scrotum</td>
<td>36.4</td>
<td>63.6</td>
</tr>
<tr>
<td>Penis</td>
<td>81.8</td>
<td>18.2</td>
</tr>
</tbody>
</table>

Sex Education
Assess knowledge and safety
• Her living/ school situation
• Daily supervision
• Her experiences with both male and females

Sex Education
Assess ability to consent

Consent and Sexual Relations
No standard screening but the following understanding should be assessed:
- That sex is a private activity that both participants want and engage in voluntarily.
- That no one can force or threaten you to have sex.
- That you can refuse to engage in sexual activity with someone even if you have agreed to engage in it before with the same person, and that it is enough to just say “no” without having to provide justification for the refusal.
- That it is not proper to have sex for money or gifts
- That it is not proper to have sex with children or immediate blood relations.

Adapted from Griffiths (Ed) Ethical Dilemmas: Sexuality and Developmental Disability, 2002
Sex Education

Give age and development level appropriate education

Education

Use Props and pictures

Language

• Repeat messages
• Keep it simple
• Positive reinforcement
• Adjust to developmental level
• Assess understanding

http://kc.vanderbilt.edu/healthybodies/girls.html
Sexual Education

• Parents are first educators
• Appropriate terms
• Focus on health and normalcy
• Private versus public: body parts and activities
• Sex, pregnancy and STI
• Contraceptive options
• Help families negotiate sexual interest and opportunities

Patient Presentation

• 15 year old patient with ID comes in for irregular periods
• Mom: “I just tell her that boys should never touch you”
• Help mom to educate patient
  – Knowledge, school issues, confidential talk?
• See them both back to reinforce
Prevention of Sexual Abuse

• Reality: People with disabilities are at increased risk for sexual assault/abuse
• Don’t deny risks, relationships, or rights
• Parents need to be alert and focus on prevention

Patient Presentation

• Farrah is an 18 year old with mild cognitive impairment
• Her mother brings her in for contraception
• Farrah goes to a regular high school and is integrated in some regular education classes
• Mother states Farrah isn’t sexually active as far as she knows but Farrah often meets men over the internet
• Mom needs help teaching Farrah about safety

Risk of Sexual Abuse

• 39%-68% of female and 16% to 30% of male developmentally disabled individuals will be sexually abused before they reach adulthood.
• Primarily male perpetrators but both male and female victims
• The largest group of perpetrators against individuals with DD are caregivers – 48%
• 65% of cases involve masturbation/touching, 31% involve actual or attempted penetration

Risk of Sexual Abuse

- 17 studies including 18,374 children with disabilities. Age birth to 21. Meta-analysis sponsored by WHO
- Pooled prevalence of violence 27% (ranges from 5-68%)
- Sexual violence pooled prevalence of 14% including 1,455 incidents in 14,675 children
- In children with mental or intellectual disability pooled violence 21% with 27% experiencing physical violence and 15% sexual violence
- Study showed that children with disabilities are 3-4 times more likely to be victims of violence than peers without disabilities


Violent victimization of persons with and without disabilities, by age, 2007

<table>
<thead>
<tr>
<th>Victim Characteristics</th>
<th>Adjusted rate per 1,000 persons age 12 or older</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Persons with disabilities</td>
</tr>
<tr>
<td>12-15</td>
<td>81.2*</td>
</tr>
<tr>
<td>16-19</td>
<td>82.7*</td>
</tr>
<tr>
<td>20-24</td>
<td>35.1</td>
</tr>
<tr>
<td>25-34</td>
<td>30.9</td>
</tr>
<tr>
<td>35-49</td>
<td>31.1</td>
</tr>
<tr>
<td>50-64</td>
<td>12.3</td>
</tr>
<tr>
<td>65 or older</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Note: Rates are based on the noninstitutional U.S. resident population age 12 or older. Adjusted rates were calculated using the direct method and the noninstitutional U.S. resident population age 12 or older as the standard. Population estimates and counts are from the Decennial Censuses (2000) and American Community Surveys (2007). Estimates are based on the American Community Survey, 2007, U.S. Census Bureau. In 2007 approximately 39,566,790 persons age 12 or older in the U.S. had a disability.


Sexual Maltreatment of students with disabilities in American Schools

<table>
<thead>
<tr>
<th>Type of Maltreatment</th>
<th>Percent of students reporting YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touched, pinched or rubbed</td>
<td>62.3</td>
</tr>
<tr>
<td>Pulled off or down clothing</td>
<td>41</td>
</tr>
<tr>
<td>Exposed private parts</td>
<td>40.4</td>
</tr>
<tr>
<td>Forced to stare in nude</td>
<td>30.1</td>
</tr>
<tr>
<td>Sexual markings</td>
<td>22.4</td>
</tr>
<tr>
<td>Sexual picture/photos</td>
<td>16.6</td>
</tr>
<tr>
<td>Forced kissing</td>
<td>14.2</td>
</tr>
</tbody>
</table>

Risk factors for Abuse

- Children with disabilities often receive praise for being friendly and cooperative
- Children with disabilities often need others’ assistance with the most private activities
- Children with disabilities may be dependent on adults for all activities of daily living
- Children with disabilities often receive little or no sex education
- Children with disabilities may be isolated from peers
- Difficult for children with disabilities to distinguish appropriate vs. inappropriate touch

REALITY: People with disabilities are at increased risk for sexual abuse


Prevention of Sexual Abuse

- Review of 6 studies reveal small number of participants, all women except one study included adolescents
- Participants were primarily mildly/moderately cognitively impaired and had verbal skills
- General teaching materials included Behavioral Skills training program (private/public, appropriate touch/behaviors), in situ training and no, go, tell
- Sessions were typically weekly for 8-10 weeks with pre and post testing
- Assessment included verbal-report, role-playing, in situ assessments and skill generalization
- Skills are learned, maintained and generalized to an extent


Prevention of sexual abuse

- ...children armed with information about personal safety are 6-7 times more likely to develop protective behavior ...
- Teach personal space and privacy by 3 years of age.
- Limit the individuals who provide genital, perianal and bathing care to those who they trust to reduce risks
- Teach appropriate names of body parts

Finkel, M.A. Child Abuse Research, Education Services (CARES) Institute The Pediatrician 2012
Prevention of sexual abuse

• Discourage co-bathing with siblings and adults.
• Introduce the concept of "OK and NOT OK" touching
• Teach that it is NEVER ok to have a "secret"
• Teach PRIVACY and reinforce the concept often
• The only people who touch private parts are parents, caregivers and doctors

Educational Goals for Prevention of Abuse and for Building Self Esteem

• Age and relationship appropriate social behavior
• Understanding sexual development and identity
• Establishing Relationships
• Boundaries
• Assertion and safety

Prevention of Sexual Abuse

Teaching boundaries – Circles

• You are the center of your circles
• No one touches you unless you want to be touched
• There are very few people who hug you
• You shake hands with acquaintances
• Wave if friends are too far away to shake hands
• Talk to helpers
• Do not talk to or touch strangers and they don’t touch you
Prevention of Sexual Abuse

• **NO - GO - TELL**: Teach the child to be their own first line of defense

• This program of prevention has been widely used, originally created for children 3-7 with developmental disabilities

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Prevention of Sexual Abuse

**NO IS ESSENTIAL**

• “The ability to make up your own mind is the first step on the way to autonomy and the ability to say, “No!” (Hingsburger, 1995)
Prevention of Sexual Abuse

TEACHING NO!

• Reinforce body privacy and say no to an unwanted touch
• Teach and rehearse saying “NO!” loudly and clearly with voice and body

Prevention of Sexual Abuse

TEACHING GO!

• Person needs to break a direct command
• Person needs to look for an avenue of escape
• Person needs to call for help/draw attention
• Person needs to know how to fight back

Prevention of Sexual Abuse

TEACHING TELL!

• Requires that a person break a promise or defy a threat
• Person needs to identify trusted others to tell
• Person needs backup plan if trusted person is doing bad touch
• Person needs to keep telling trusted others until someone listens and takes action
Patient Presentation

• Upon further questioning boys had touched Farrah inappropriately at school
• Her “friends” tried to convince her it would be cool to get pregnant
• Men on the internet had asked her to send pictures of her breasts and she willingly did it
• She gave another man her address – he said that he wanted to marry her and he would come visit

Internet safety —
National Children’s Advocacy Center

1. If anything makes you feel uncomfortable online, talk with your parents or guardian right away.
2. Never post your personal information, such as a cell phone number, home number, home address, or your location on any social networking site or through mobile apps like Snapchat or Instagram.
3. Never meet in person with anyone you first “met” on the internet. If someone asks to meet you, tell your parents or guardian right away. Some people may not be who they say they are.
4. Check with your parents before you post pictures of yourself or others online. Do not post inappropriate pictures of anyone.
5. Never respond to mean or rude texts, messages, and e-mails. Delete any unwanted messages. You may need to delete friends who continuously bother you or post things that are not appropriate.

Tools for providers
American Academy of Pediatrics - Preventing sexual violence Tool kit Web version 2010

• Build a relationship with the family. Be respectful and nonjudgmental.

• Take a complete social history that examines the context of the child’s life at each of these levels.

• Videos available that demonstrate history taking skills for all age groups and mnemonics to remember all topics to address FISTS [Fighting, Injuries, Sex, Threats, Self-defense]
Tools for teaching – Boardmaker
What is bad touch

- A bad touch is when someone tries to kiss you or touch your body on your thigh area, on your butt, or your genital area. This is called an inappropriate touch.

Tools for teaching – Speak up
Communicating about sexuality

- and more...

Physical Signs of Sexual Abuse

- Difficulty with walking or sitting
- Torn or bloody underwear
- Genital or anal bruises or bleeding
- Genital or anal itching or pain
- Pregnancy or STD
Behavioral changes related to Sexual Abuse

<table>
<thead>
<tr>
<th>Type of behavior or symptom</th>
<th>Percent of informants reporting symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss in interest in activities</td>
<td>76.5</td>
</tr>
<tr>
<td>Inappropriate behaviors</td>
<td>72.2</td>
</tr>
<tr>
<td>Avoiding cues</td>
<td>99.0</td>
</tr>
<tr>
<td>Remember</td>
<td>96.7</td>
</tr>
<tr>
<td>Avoiding people</td>
<td>96.9</td>
</tr>
<tr>
<td>Regression of behaviors</td>
<td>96.9</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>96.8</td>
</tr>
</tbody>
</table>


Evaluation for Sexual Abuse

• For an Acute event:
  – Seek medical evaluation up to 120 hours
  – Rape evaluation can be performed for forensic evidence by a forensic medical clinician
  – Evaluation for injuries, photos may be taken, clothing may be saved for evaluation
  – Test for infections, collect swabs for evidence
  – Provide Antibiotics, EC and PEP
• For a long term concern:
  – Seek medical evaluation with clinician who has experience with sexual assault
• Evidence is difficult to obtain unless an STD is present
• A normal exam does not rule out abuse!!

Chave-Cox, RS. Journ Forensic and Legal Medicine 25 (2014) 71-75

QUESTIONS?