

## Puberty and Down Syndrome

Down Syndrome Guild of Kansas City  
Keys to Success Conference  
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## Goals

- Review basic physical and behavioral changes of puberty
- Present some basic strategies for teaching your teen with DS about puberty
- Discuss several common concerns for parents of adolescents with DS

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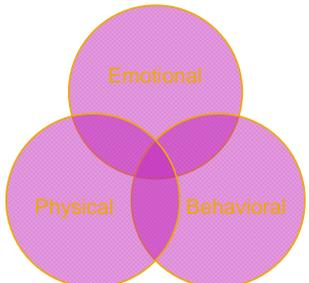
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## Changes During Puberty



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## Physical Changes

- Most children with developmental disabilities go through the physical changes of puberty at typical times
- The early physical changes of puberty continue to occur at earlier ages for all children





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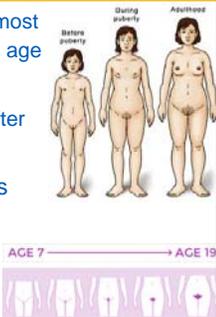
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## First Signs of Puberty in Girls

- The first physical sign of puberty in most girls is "breast budding." The typical age for this is 10 years (8-13 yrs)
- Pubic hair usually appears shortly after the development of the breast buds.
- Growth spurt also begins around this time.





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## Bra Basics



- Wearing a bra
  - Begin before it is "necessary" to allow time to adapt and to learn independent dressing skills
  - Consider various factors when deciding which types of bras to select
    - Fine motor and motor planning skills
      - OT may be helpful in developing task analyses or strategies
    - Sensory sensitivities
    - Flexibility/resistance to change
      - May want to begin teaching with a regular bra vs. training/sports bra if you have a family history of larger breasts




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## Puberty in Girls



- Pubertal changes and gain in height continue for the next 1½ - 2 years, on average.
- Increase in vaginal fluid is often noted (leukorrhea).
- Menstruation usually begins around age 12 (10-15 yrs).
- Little growth typically occurs once periods begin.




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## Menstruation

- Menstrual patterns in girls with DS are not different from typical girls.
- For all adolescents, menstrual cycles are often irregular or unpredictable at first but then become more cyclic.
- Girls with DS who have good self-care skills are able to take care of menstrual hygiene.




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## Menstrual Hygiene

- Begin practicing before it is necessary!!!
- Utilize various tools for teaching
  - Pictures, drawings, written lists, books
- Have her try out the feel and fit of a variety of pads
- Many girls will benefit from the use of a task analysis (often with visuals) to teach changing a pad
- This should be practiced at home, school, and in the community




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## Menstrual Hygiene

- Helpful hints and adaptations
  - Use a brown paper bag for girls who do not have the fine motor skills to fold and wrap a pad
  - Wear dark pants and underwear during period
  - Use thicker/longer pads or ones designed for incontinence for girls who may forget to change pads during school



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## Menstrual Hygiene

- School hints and adaptations
  - Designate a person in school who can assist with menstrual hygiene if needed
    - This person should keep an extra set of clothes and extra pads
  - Select an unobtrusive clutch or pencil bag to carry supplies to the bathroom
    - She should have this in her school bag at all times



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## Fertility in Girls and Women with Down syndrome

- Females with Down syndrome are fertile and capable of conceiving a pregnancy.



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### Medical Management of Periods

- Various contraceptive medications can be used to try to shorten and lighten periods, reduce their frequency and/or reduce their discomfort.
- No medication will completely prevent menstruation. Girls will still need to know how to care for their periods.



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### Oral Contraceptive Pills

- Use over time usually results in shorter, lighter menses.
- Can manipulate pills to reduce the number of periods – extended cycling possible
- Require daily compliance
- Now available in a chewable form



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### Birth Control Patch (Ortho-Evra™)

- Same hormones as pills, just different delivery system
- Safety with continuous use?
- Not for “pickers!”



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### Birth Control Ring (Nuvaring™)

- Same hormones, different delivery
- Has been used continuously with good results
- Must be able to insert it, check regularly



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### Depot-medroxyprogesterone acetate (DMPA, Depo-Provera®)



- Long history of use for menstrual suppression
- Easy to use
- Rare contraindications
- Breakthrough bleeding very possible
- Can stimulate appetite
- Bone health concerns (FDA "black box" warning)



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### Etonorgestrel implant (Nexplanon™)

- Irregular bleeding is most common side effect
- Requires cooperative patient for insertion
- Excellent contraception
- Lasts 3 years



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### Levonorgestrel-releasing intrauterine system (IUS) (Mirena®)

- Irregular bleeding at first, followed by decreased menses
  - 90% with decreased flow
  - 50% stop having periods
- Requires cooperative patient for insertion
- Uterus must be of adequate size



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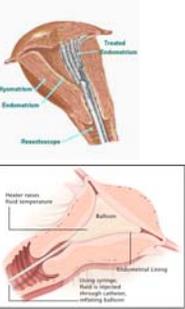
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### Surgical Management of Menses - Endometrial Ablation



- Alternative to hysterectomy
- May have regrowth of endometrium
- Should be considered as sterilization – though pregnancies can occur
- Ethical and legal issues

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### Surgical Management of Menses - Hysterectomy

- Sterilization
- Ethical and legal issues



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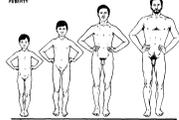
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## Puberty in Boys

- Pubertal changes in boys are a little less predictable in their sequence and timing.
- The first sign of puberty in boys is enlargement of the testicles. The average age for this is 11 years (9-13 yrs).
- Over the next several year, the penis and testicles continue to grow to their adult size. Growth is usually complete in the middle teen years.



PHOTO



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## Puberty in Boys

- Boys are often well into puberty before their growth spurt begins.
- There is not marker (like menstruation in girls) to signify that the growth spurt is ending.
- The growth spurt typically is over around 15-16 years of age.



Age 9 → Age 19



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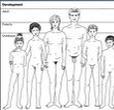
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## Growth Spurts & Muscle Growth

- During times of growth, children may become more clumsy and uncoordinated
- Boys' strength increases dramatically as muscles grow and develop
  - Importance of behavioral management before puberty
  - Often not aware of own strength
  - Prompting and physical management becomes more difficult



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## Puberty in Boys

- More subtle pubertal changes like voice changes and increased facial hair are quite variable in their timing.



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## Voice and Hair Changes

- Voice changes may be difficult
- Some children become distressed when hair grows “where it shouldn’t”
  - Reassure that it is normal-pictures may help
  - Watch for hair cutting and pulling



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## Sexual Functioning in Boys

- Boys with DS do have erections and ejaculations.
- Fertility in boys with DS appear to be decreased but there have not been good studies on this.



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## Spontaneous Erections

- Reassure about normality
- Teach and review how to best cope
  - Remain seated
  - Do not touch yourself
  - Use a book or shirt to cover yourself
  - Don't comment
- Hints
  - Briefs may be better than boxers
  - Some pants hide them better than others
  - Positioning



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## Wet Dreams



- Wet dreams can be scary and/or embarrassing
- Prepare ahead of time using language at the child's level of comprehension and normalize
- Explicitly teach what should be done when they occur
  - Change pajamas, wash himself, etc.



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## Emotional and Behavioral Changes with Puberty

- All youth experience emotional and behavioral changes during puberty and adolescence
- Emotional and behavioral changes may begin before or during physical changes and are highly variable and individual



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### Emotional Changes and Behavioral of Puberty...for All Teenagers!

- Striving for greater independence
- Questioning family and school rules
- Moodiness
- "Attitude"
- "Drama"
- Increased aggression
- Non-compliance
- Need for more sleep



**Questions**

**DRAMA**



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### Puberty is an Exciting...and Sometimes Frustrating Time For Any Parent



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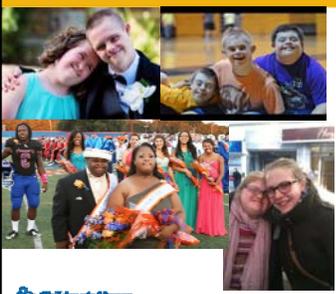
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### All Children Experience Similar Changes as They Go Through Puberty But...



Adolescents with DS may face them without the same preparation or understanding



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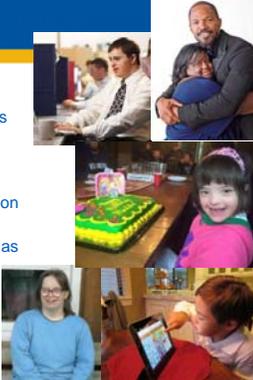
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## Challenges for Individuals with DS

- May not, or cannot, ask questions
- May ask questions at less than ideal times
- Limited peer contact
- Require more explicit & repeated instruction
- Parents don't think of their children/teens as sexual beings
- Communication & cognitive impairments



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## Preparing for Puberty with Your Child

- Begin early
  - Parents need time to gather resources, materials, etc. that are appropriate for their child...and to become more comfortable with the process.
- Put yourself in your child's place and think about what he or she will experience.
- Use direct teaching



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## How to Teach about Puberty

- Teaching should be geared toward social and cognitive levels
- Magical thinking about body changes
- Coordinate curriculum with the school if possible
- Use concrete approaches
  - Multiple modalities
  - Frequent repetition
  - Check for comprehension



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### Individualized Instruction For Individuals with DS

- Concrete
- Brief, specific, and clear
- Use visuals
- Teach hygiene in real life settings
- Repeat frequently



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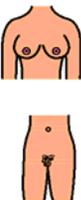
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### Sex Education for Individuals with DS

- Body parts and function
- Physical maturation
- Personal hygiene & self-care
- Health
- Appropriate social & sexual behavior
- Privacy issues



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Sullivan & Caterino, 2008

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### Sex Education for Individuals with DS

- Understanding emotions and impulses
- Self-image
- Abuse prevention
- Assertiveness
- Attraction
- Interpersonal relationships



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Sullivan & Caterino, 2008

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## Same Gender Interests/Relationships

- No reason to suggest that rates would differ from the general population
- Situational factors (e.g., male majority in special education programs, same gender only living facilities)
- Very limited research base
  - Often parental/caregiver report
  - No one is asking!
  - Cannot know the thoughts and feelings of individuals with limited communication



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## Curiosity about Bodies and Sex

- Often initial absence or reduction of curiosity and exploration
- Modesty is socialized – incidental learning is not enough for individuals with developmental disabilities
- Nakedness – when and where it's OK – be explicit



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## Modesty

- Acceptability of nudity for young children is different from that of teens and adults.
  - Not a natural instinct – guided by society
  - Social concern
  - Safety concern



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## Modesty

- Be clear and definite in your teaching of appropriate places to be naked
  - Bathroom & bedroom
  - Alone with the door shut
  - Locker room?
  - Doctor's office
- Be clear and definite in your teaching of who can see the child naked



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## Boundaries

- Transition from hugs to high fives
- Who can touch as well as where and when
- Time and place to talk about sexuality and puberty
- Who is OK to talk with about these issues and when
- Boundaries are learned



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## How to Teach Boundaries

- Be explicit about who can touch and where they can touch
- Compliance training
  - Facilitate opportunities where it is OK to say no
- Encourage members of the family to model respect for privacy (e.g., when using the bathroom, getting dressed)



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## Personal Care May Need More Guidance



- Encourage independent dressing from an early age
- Regular bathing
  - May need some direction in how to properly wash
  - Transition from bath to shower



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## Hygiene

- Start before adolescence
- Think about motor planning and fine motor skills
- Include goals in IEP
- Encourage independence with explicit teaching & repetition
  - Teach washing genitals first
- Transition from tub to shower
  - Liquid soap/shampoo in pumps
  - Checklist of steps



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## Public Restrooms

- Family bathrooms are great for younger and/or more impaired individuals
- Boys need explicit training with urinals
  - look forward
  - where to stand
  - don't make comments or chat



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## Masturbation

- Masturbation begins in the womb but becomes more frequent during the teen and preteen years.
- It is a normal part of development for both boys and girls as well as those with and without disabilities.
- Typical kids quickly pick up on the "rules" but those with developmental disabilities may not.



RULES

1. YOU CAN....
2. YOU CAN'T...
3. YOU CAN...
4. YOU CAN'T




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## Masturbation

- Often significant concern for families and schools
- It is a normal behavior but challenges are common
- Professionals need to address this issue explicitly with parents and with teens (as appropriate to their developmental level)

no



hands



in



pants



masturbation



masturbation



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## Masturbation for Males

- Direct and explicit teaching of :
  - Masturbation without injury (e.g., use of lubricant)
  - Cleaning up afterwards
  - Where it is appropriate
- Occasionally require professional assistance to learn how to masturbate to orgasm effectively-AAST
- Redirecting with minimal attention is often the best way to deal with public masturbation or "hands in pants"
  - Visual prompts
  - Signal
  - Environmental/clothing modifications




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## Masturbation for Females



- Not usually as much a concern of families or professionals as with boys
  - Inappropriate masturbation may be more subtle but does occur
- Girls may masturbate with objects, on furniture, by muscle tensing, etc.
- May require guidance in how to effectively masturbate to orgasm
  - Educational materials
  - Professional assistance-AAST
  - Vibrators, sex toys, etc.
- If there is a sudden increase in genital rubbing and/or touching, consider a yeast infection, urinary tract infection, vulvovaginitis, or other irritant




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## Private Time



- Parents should consider designated “private time” in bedroom with door closed
  - Scheduled
  - Redirected when needed
- Limit masturbation to bedroom with door closed vs. the shower/bathroom
- Parents should teach and respect privacy (e.g., knock if child’s door is closed)




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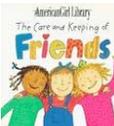
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## Lack of Filter




- Discrete signal to stop topic/questions
- Debriefing after the incident-social autopsies
- Use of books/movies for faux pas lessons
- American Girl books
- Direct instruction on what is appropriate to talk about and with whom and where







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## Take Home Messages



- Youth with DS go through most of the same challenges during puberty as do those without disabilities but...
  - They often face them without the same preparation or understanding
  - This can lead to inappropriate behaviors and unnecessary stress for both children and families




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## For Families





- Begin early!!
  - Prepare yourselves and your child
- Teach using ways that he or she can understand
  - Visuals 
  - Lists
  - Modeling
  - Books 




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## For Families & Professionals

- Put yourself in the child's place and think about what he or she will experience- preventative maintenance!
- Teach and practice before you need to-be proactive!
- Encourage independence as much as possible
- Plan ahead!







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## For Professionals

- Begin the discussion with parents when their child with DD/ASD is young
- Provide resources to families
- Encourage parents to put themselves in their child's place and think about what s/he will experience-practice preventative maintenance!
- Encourage developmentally appropriate independence and skills

**TALK ABOUT IT!!**

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## Important to Remember...

- Everything from modesty to boundaries to hygiene are social constructs which need to be explicitly taught to children with developmental disabilities

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## Summary

- Puberty is a similar series of physical, emotional and behavioral changes for both typical adolescents and those with DS.
- Adolescents with DS usually need more specific and repeated instruction about puberty.
- Puberty is an exciting time as you watch your child grow into a young adult!

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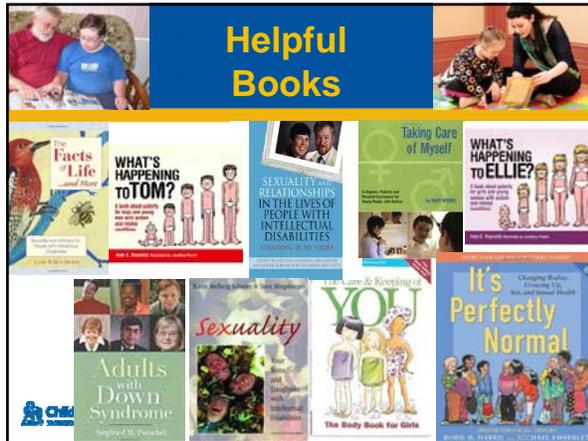
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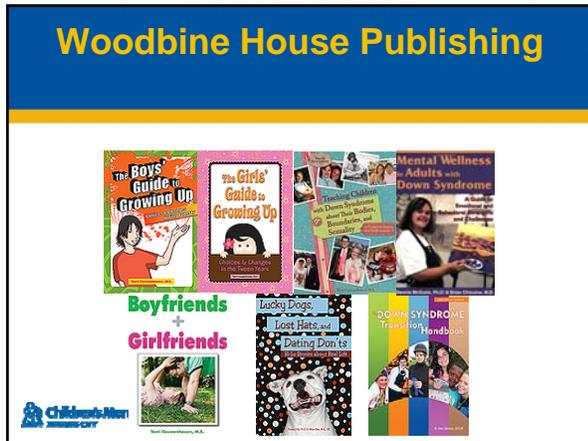
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## Thank you!

- Collaborators on related talks:
  - Lisa Campbell, MD
  - Celeste Flachsbart, PhD
  - Carol Garrison, MD
  - Rochelle Harris, PhD
  
- The many individuals with DS and their families with whom we have had the privilege to know and to learn from



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## SIECUS' Policy Statement

SIECUS believes that individuals with physical, cognitive, or emotional disabilities have a right to education about sexuality, sexual health care, and opportunities for socializing and sexual expression. Healthcare workers and other caregivers must receive comprehensive sexuality education, as well as training in understanding and supporting sexual development, behavior, and related healthcare for individuals with disabilities. The policies and procedures of social agencies and healthcare delivery systems should ensure that services and benefits are provided to all persons without discrimination because of disability.



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## The Arc's Statement

For decades, people with intellectual disabilities and/or developmental disabilities have been thought to be asexual, having no need for loving and fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has negatively affected people with intellectual disabilities in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with intellectual or developmental disabilities frequently lack access to appropriate sex education in schools and other settings. At the same time, some 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.

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.



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