# Puberty: Changes, Challenges, and Triumphs

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# This is going to be fun!

Right?

### Why Are We Here?

To learn more about puberty

 Increase knowledge and strategies to discuss puberty with children and adolescents

#### Knowledge is Power!



- A positive attitude and psychoeducation provides an opportunity to:
  - Develop positive sexual self-view
  - Build confidence and self knowledge
  - Decrease risk for dangerous situations
  - Redirect inappropriate behaviors
  - Assist with assertive communication and the ability to advocate for needs
- Lack of education about puberty and sex education puts teens and young adults with disabilities at greater risk of abuse (Murphy & Elias, 2006).

## Puberty- It's Normal!

•Every person goes through puberty and has sexual desires and curiosities.

 Puberty and interest in sex happens whether parents, teachers, or kids and teens are ready or

not!



#### Outline

- Onset of puberty
- Sex education for children/adolescents with disabilities
- Special considerations/Birth Control Options
- Preparing for medical visits
- Tips and techniques about how to talk to children/adolescents and strategies to manage changes that happen during puberty
- Identity development
- Victimization prevention and safety
- Resources

### What is normal puberty for boys?

- Most boys start genital development about 11.5 years.
- Testicular enlargement is the first sign of puberty in most boys.
- Abnormal:
  - testicles enlarge before age 9
  - no development after 14

### What is normal puberty for girls?

- Mean age of onset (Breast changes) is 8.9
  years for African-American girls, 10 years for
  white girls.
- Mean age of first period is 12 years 4 months, happens a year after growth spurt
- Abnormal:
  - breast development before age 7
  - no period by 15

# Adolescents with disabilities and chronic medical or chronic mental health conditions

Often perceived as asexual or "childlike"

Conversely, may be perceived as overly or inappropriately sexual or with as having uncontrollable urges

Often suffer negative body image and low self-esteem

Parents may fear their children are at risk of sexual abuse

Children who have disabilities are sexually abused at a rate of 4.6 times higher than for children who have no disabilities\*

These factors may lead to parental and societal overprotection, and can affect the ability of these individuals to establish relationships with peers





#### Sex Ed and Special Education:

Should be comprehensive

Information presentation may need modification for youth with disabilities

Simplifying information

Teaching in special needs rather than mainstream classroom setting

Using teaching materials such as anatomically correct models, role playing, and review and reinforcement of material

Individualized Education Plans (IEP) should include the provision of sexuality education

# Topics to include in sexual education plan

- Body parts
- Pubertal changes
- Personal care and hygiene
- Medical examinations
- Social skills
- Sexual expression
- Contraceptive strategies
- Rights and responsibilities of sexual behavior



# Gynecologic Health of Adolescents with Disabilities

Comprehensive

Maintain confidentiality if possible

Does not treat the patient as infantile

Maximize patient's interests

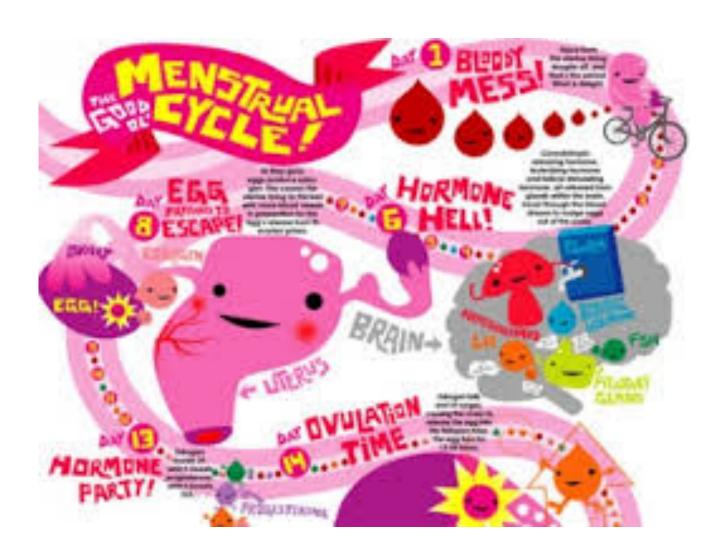
Avoid harm

Direct communication to the teenager rather than the caregiver

Assess knowledge of puberty, menstruation, sexual activity, safety, and the ability to consent to any sexual act

Provide developmentally appropriate education

### Menstruation



#### What are normal menstrual periods?

- Cycle length 21-45 days
  - Period Tracker or Pink Pad helpful
- 3-7 days bleeding
- When in doubt, get a blood count
- Let MD know if skips > 3 months

#### Other Menstrual Concerns

 Irregular cycles during the first 2-5 years after menarche typical of normal development

- Some issues unique to adolescents with disabilities:
  - Thyroid disease in trisomy 21
  - High prolactin levels due to mood stabilizing medication
  - PCOS in teenagers with seizure disorders

#### Requests for menstrual manipulation

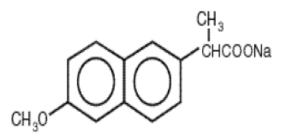
Convenience for family or caregivers

Vulnerability for abuse and pregnancy

#### Menses affecting patient's quality of life:

- Inability to participate in usual activities during menses due to:
  - inadequate help with hygiene needs
  - behavioral issues during menses
  - dysmenorrhea

# **Treatment Options**





Naproxen sodium

**NSAIDs** 

#### Estrogen-containing methods

- Combined oral contraceptive
- Contraceptive Patch
- Contraceptive Ring
- Consider estrogen use and risk of DVT



# Progestin-only methods

- Oral
- Implants
- Intramuscular injection (DMPA)
- IUD

# Special consideration: Antiepileptic drugs and hormone use

Contraceptive
effectiveness
may be affected
by enzyme
inducing anti
epileptic drugs.

Progestins increase seizure threshold

Estrogen or progesterone content may need to be increased or DMPA may be used in 10 week intervals to decrease irregular bleeding

Even though estrogen is a proconvulsant, combined OC's have not been associated with an increase in seizures

Think about your patients on teratogenic drugs (i.e., depakote, methotrexate) and ask if they are using birth control!



\*"Individuals with disabilities are often not supported - or even vehemently discouraged - if they choose to have children." \*"Sterilization - often involuntary - is commonly used as a solution to deal with the reproductive health of individuals with intellectual disabilities."

# What should my child's health care provider be doing?

- Anticipatory guidance
- Practicing confidentiality/time alone OR REFER OUT
- HPV vaccine
- Asking about relationships/ coercion
- Asking about gender identity and sexual orientation
- Screening for STIs/HIV
- Pap not until 21 years
- Consider GYN referral at age 13 (ACOG)



#### Tips and Techniques

- Start early
  - Changes in routine
- Ask What They DO Know
- Creating a Comfortable Environment
  - Work on an activity
  - Sit side-by-side
  - Go for a walk
- Be truthful
- Consult
- Values
- Normalize anxiety, confusion, and fears!
  - Always check-in and address any feelings and concerns that arise when talking about puberty

#### Language

- Keep it simple and concrete
- Use correct terminology when you can

Not just the "what" facts, but more importantly

"why"



#### Language

Vague

leaves the door open for misinterpretation

Specific

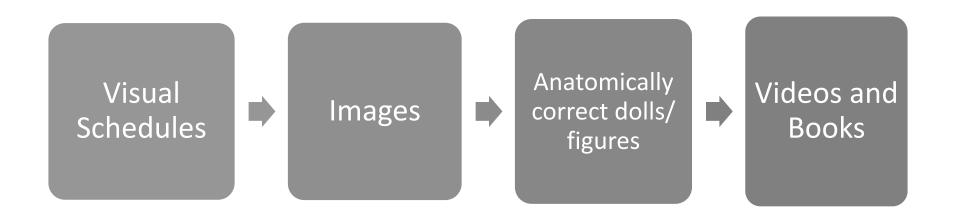
detailed, structured, creates a conversation

"You can't get pregnant until you're married."



"You can become pregnant by engaging in vaginal intercourse. Let's talk more about what that means."

#### Visuals



#### Benefits of a visual schedule

✓ Explains the what and the why

✓ Provides a visual

✓ Concrete and easy to follow

✓ Provides structure and routine

Wash your body with soap in the shower.
 Wash your hair with shampoo.
 This cleans your body and gets rid of odors.





2. Brush your hair to get rid of tangles.



3. Brush your teeth to get rid of bad breath and food particles.



4. Put on deodorant. It helps prevent sweating and body odor.



5. Dress yourself in an outfit that covers your body, matches the weather (and is okay for your dress code). This increases confidence and comfort



#### Visual Schedules





#### **Social Stories TM**

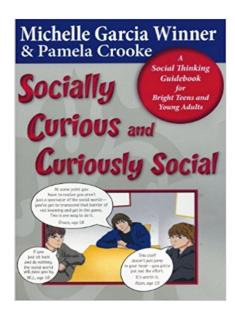
#### Social Stories<sup>TM</sup>

- Available for free at: http://raisingchildren.net.au/articles/autism\_spectrum\_disorder\_periods.html
- Cover topics such as 'getting your period' and 'wet dreams'
- Provide concrete information to individuals who are more verbal

#### Socially Curious and Curiously Social

(Garcia Winner & Crooke)

- Covers topics related to adolescence
- Uses concrete visual/verbal examples



### Social Story Example

- Social Story: I will begin to have my period
- •As my body changes I will get my period.
- •When I get my period, blood comes out through my vagina.
- •I will need to use a cloth, pad or tampon so my clothes don't get stained.
- •Most girls and women have a period every 28 days. Sometimes it might be sooner or later. This is OK.
- •A few days before I get my period, I might feel more upset about things. I might feel angry, I might feel sad, I might feel frustrated, or I might feel other emotions. Feeling this way is normal and usually stops when my period starts.
- •My breasts, stomach and the lower part of my back might feel sore at this time. This is normal.
- •Putting a hot water bottle on my stomach and having some pain relief medication can help me feel less sore.
- •I might have my period for 4-7 days. It might be shorter. This is OK.
- •If my period goes for longer than seven days, I will talk to an adult who cares about me.

### Social Story Example

- When I am sleeping, I might have a dream.
   When I wake up, my sheets might be sticky and wet. This is called a wet dream.
- When I have a wet dream, I should always wash my testicles (balls) and penis when I wake up.
- Wet dreams happen to lots of boys.



I'm Growing Up



I used to be a small boy Now I am a young man





My body is changing



This is a good thing!



I'm getting taller



Soon I will have more hair on on my legs



Hair will grow under my arms



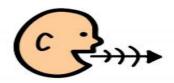
I might grow chest hair



And I will have pubic hair near my private: hair will grow on my face



When I am about 15,



My voice will sound lower



My penis is also growing



Soon, I will put on deodorant every day



Dad and Mom will show me how to shave



These changes happen to all boys



Sometimes, I might feel embarrassed about these changes



Sometimes, I might feel proud!



It's okay to ask questions about these changes



My parents love me and they understand

I'm Getting Older: For Boys

#### **Gradual Exposure**

#### **Menstruation**

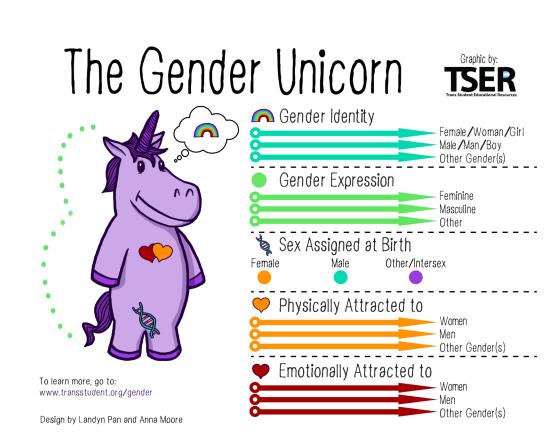
- Picking out supplies
- Practice wearing pad in underwear
- How to carry supplies at school/out in public
- Who you can and should not talk to about your period
- https://www.shethinx.com/

#### **Shaving**

Gradual desensitization to noises and sensations

### **Identity Development**

- Increased interest in friends
- Social Media
- Crushes
- Dating
- Sexual orientation
- Gender identity



#### Victimization

- 2.2 x higher rates in children with developmental delays (National Center on Child Abuse and Neglect)
- 68-83% of women with intellectual disability will be sexually assaulted in their lifetime; less than half will seek legal assistance or treatment (U.S. Justice Department)
- Among adults with ASD, rates of unwanted sexual contact were 3x higher, sexual coercion was 2.7x more likely, and rape was 2.4x more likely (Brown-Lavoie et al., 2014)

#### Risk and signs of abuse

#### **Possible risk factors**

- increased dependence for intimate care
- increased # of caregivers
- reduced social skills
- reduced judgment
- inability to seek help / report abuse
- decreased access to information

#### Possible signs

- altered bowel/bladder patterns
- altered appetite
- altered sleep
- altered mood
- altered behavior
- altered community participation

→ but doesn't always mean abuse

#### **Prevention and Safety**

Public versus Private

Interrupting

Redirecting





#### **Sort Board**









by Life Enrichment Classroom, Cardinal Cushing Schools.

#### Good Touch/Unsafe Touch

"Good touch helps us feel safe. Sometimes we may want a hug and can ask for one. Some examples of safe touch include hugs, high fives, fist bumps or holding hands." "Unsafe touch is anything that makes us feel uncomfortable, embarrassed, angry or upset. Some examples include hitting, kicking, slapping, biting, poking, asking to see private body parts, any touch to the "swimsuit area", "pantsing" (pulling down someone's pants or giving a "wedgie"

https://www.tasccalberta.com/healthy-boundaries-disability/

#### Circles Curriculum

- Designed for children and adolescents with an Intellectual Disability
- Teaches about 6 different circles
- Circles represent varying degree of closeness
- Ranging from relationship with self to

strangers



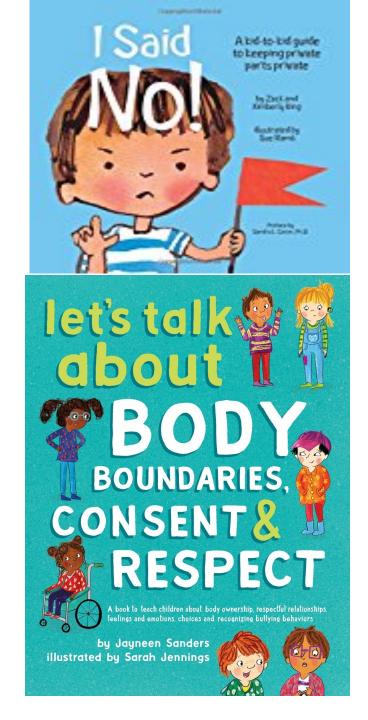
https://www.stanfield.com/product/circles-curriculum-bundle-w1004-38/

#### My Body Is My Body - Song Lyrics

https://www.mybodyismybody.com/my-body-is-my-body
It's my body
My body
And nobody has a right to hurt me
'Cos my body is my body for me
It's my body
My body
And nobody has a right to touch me
'Cos my body is my body for me

I've got two hands to feel
And two eyes to see
And two ears to hear what you're telling me
I've got two strong legs to take me where I go
And I've also got some private parts
That I don't want to show

It's my body
My body
And nobody has a right to hurt me
'Cos my body is my body for me
It's my body
My body
And nobody has a right to touch me
'Cos my body is my body for me



#### Consent

#### YES MEANS YES

learn about what consent should look like!



#### INFORMED CONSENT

You and your partner should both know all the risks (do you know if you have any \$TIs?) and activities (do you plan to have sex?) involved.



#### ENTHUSIASTIC CONSENT

You and your partner should both want to participate! If either of you is feeling less than excited about it, stop and re-evaluate.



#### CONTINUOUS CONSENT

Consent to one act, like kissing, does not imply consent to another one, like oral sex. You and your partner need to check in throughout the experience!



#### **CONSENT WITHOUT COERCION**

four consent and your partner's should not hinge on any kind of fear, discomfort, or pressure. Don't, for example, keep asking to do something until your partner says yes.

That's not consent.

### Repeat Repeat!

 Learning and Behavior should be modeled, discussed, and practiced over and over.

 Always leave the discussion open for additional questions.

#### What We Can Do!

 Provide the support, resources, and tools to educate those with disabilities about puberty, boundaries, and sexual health!

#### FLASH lesson plans for Special Education

While transparencies are embedded in some of the lessons, they have also been pulled out and separately indexed in PowerPoint format to make it easier to access and print those off.

Section	Title	PowerPoint	Updated
Overview	Overview		Jan./12
Lesson 1	Introductory Class	PowerPoint	Dec./05
Lesson 2	Private & Public		Dec./05
Lesson 3	Relationships, Day 1: Self-Esteem	PowerPoint	June/13
Lesson 4	Relationships, Day 2: Gender Identification		June/13
Lesson 5	Relationships, Day 3: Families		June/13
Lesson 6	Relationships, Day 4: Friendships & Dating		June/13
Lesson 7	Relationships, Day 5: Acquaintances & Strangers	PowerPoint	Dec./05
Lesson 8	Communication. Day 1: Non-Verbal Communication		Feb./06

#### Resources

https://www.mass.gov/files/documents/2016/07/xe/hrhs-sexuality-and-disability-resource-guide.pdf

https://www.tasccalberta.com/

https://www.parentcenterhub.org/

https://vkc.mc.vanderbilt.edu/healthybodies

Attwood, S. (2008). Making Sense of Sex a forthright guide to puberty, sex, and relationships for people with Asperger's Syndrome. London, UK: Jessica Kingsley Publishers.

Health (2011). Retrieved from <a href="https://www.autismspeaks.org/sites/default/files/documents/transition/health.pdf">https://www.autismspeaks.org/sites/default/files/documents/transition/health.pdf</a>

Henault, I., and Attwood, T. (2006). *Asperger's Syndrome and Sexuality From Adolescence Through Adulthood.* London, UK, Jessica Kingsley Publishing.

Sexuality Resource Center for Parents (2015). Retrieved from <a href="http://www.srcp.org">http://www.srcp.org</a>

youngwomenshealth.org

https://www.stanfield.com/product/circles-curriculum-bundle-w1004-38/

# Questions/ Thank You!