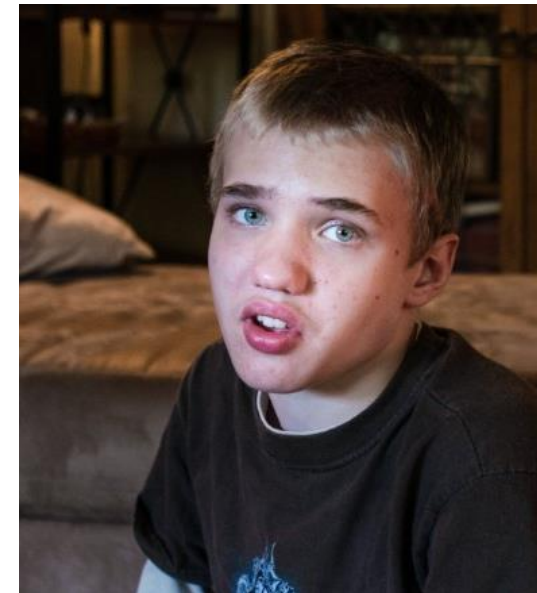
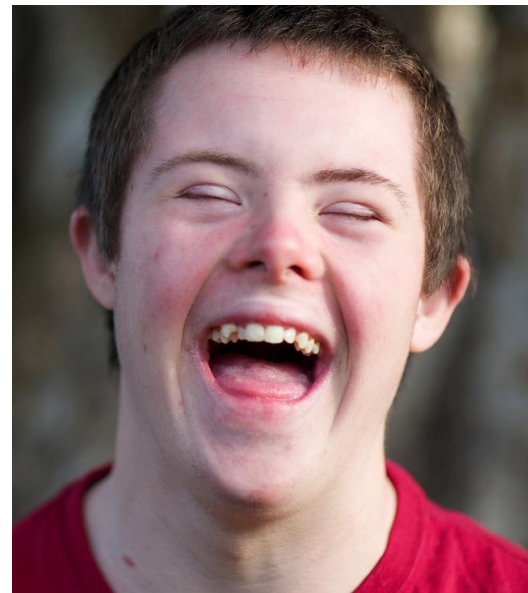




Puberty and Children with Complex Health Conditions and/or Disabilities

Cathy Haarstad



Puberty and Children with Complex Health Conditions and/or Disabilities

Rule # 1 Puberty happens for most children with complex medical needs or disabilities regardless of how you feel about it as a parent or how your son or daughter feels as a person.

Rule # 2 You can't change rule number 1.

About Puberty

Children with disability often experience delays in achieving milestones. We may think that puberty may occur later or not at all for our child with a disability.

However, for children with a disability puberty usually occurs at the same age and rate as typically developing children.

Puberty is a life stage, not an event! Puberty is the process of growing from a child into an adult and happens to everyone starting as early as 8 years and ending between 17 and 20 years.

Social and Emotional Development

Social changes and emotional changes show that your child is forming an independent identity and learning to be an adult.

The rate of social and emotional development varies widely, both for typically developing children and children with a disability

What Should I
Expect?



Change!

Mood
changes

Sleep
changes

Brain
changes

Hygiene
changes

Clothing
changes

Behavior
changes

Body
changes

Social
changes

Sexual
changes



Signs of Change in Social/Emotional Development

- Have difficulties monitoring and expressing emotions
- Difficulties with peer and social relationships
- Might have difficulties making and keeping friends
- Moodiness, has more arguments with you
- Sees things differently from you
- Antisocial behavior and risk-taking behavior
- Difficulties balancing emotions and behavior
- Wants to spend less time with family



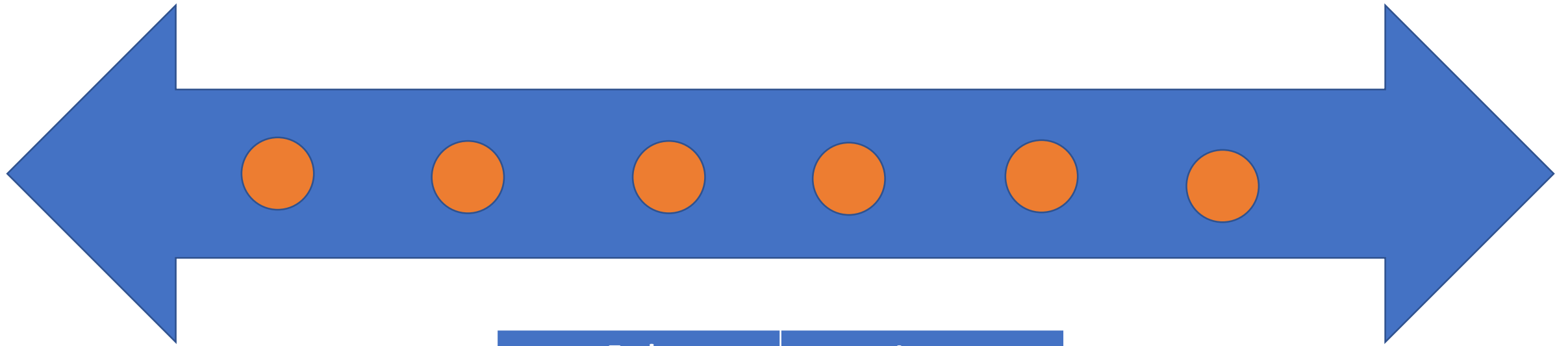
Changes My Child Needs To Know About

**Changes
Other
People
Will See**

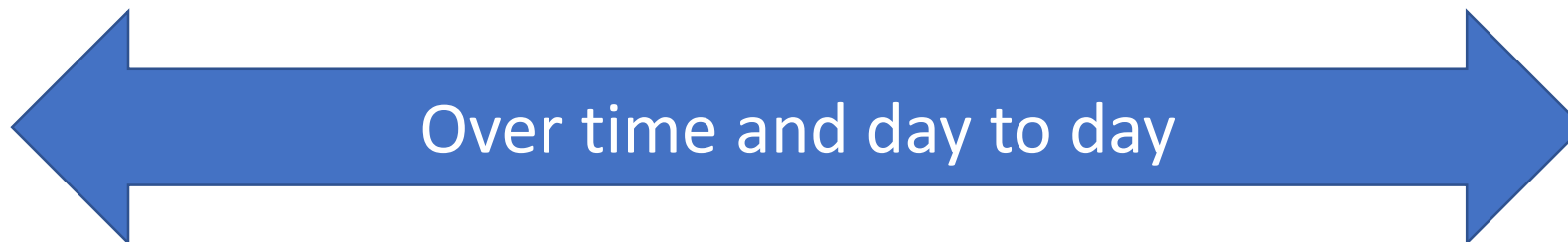
**Changes Only
You &
Your Doctor
Will See**

**Expected
Changes in
Behavior**

Prepare for Differences in How Puberty Rolls Out



Early	Late
Typical	Atypical
Mild	Intense



Parent Reactions

Why does he/she
have to be
completely normal
in this one area?


I think I'll go work in
the garage now!

I don't like questions
like that!

You have to take
him/her for a while
because if I keep
him/her with me I
might kill him.

I think it's time for
YOU to have the talk
with him/her!

You're so much
better at stuff like
that.



Get Information About Puberty ~~Before~~ It Happens



WHEN

- Learn what people whose gender is different than your own experience during puberty.
- Get medically accurate but readable information.
- Brush up on what you know.
- Find out about differences in puberty (if any) related to your child's disability (if known).
- Find natural partners who can help you navigate whatever happens until you reach a new normal.



Our Role as Parent & Teacher

- [Bodies and body parts: teaching children with ASD](#)
- [Boys' bodies and girls' bodies](#)
- [Public vs private body parts](#)
- [Personal boundaries and safety: good touch and bad touch](#)
- [Personal boundaries and safety: unwanted touch](#)
- [Circle of friends](#)



Why Give Information to Your Child

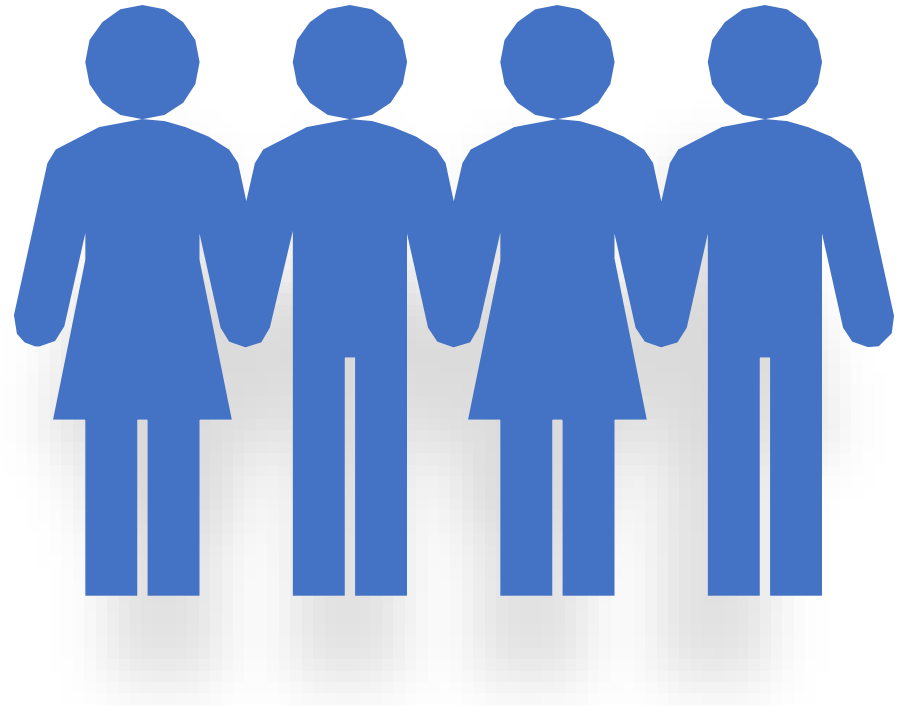
- Decreases the Likelihood of Abuse
- Combats Myths & Misinformation
- Promotes Social Skills, Personhood, Pleasure
- Reduces Fear, Anxiety, Worry
- Increases Self-Awareness, Gender Comfort
- Allows for Maturity, and Healthy Relationships

Storyboard

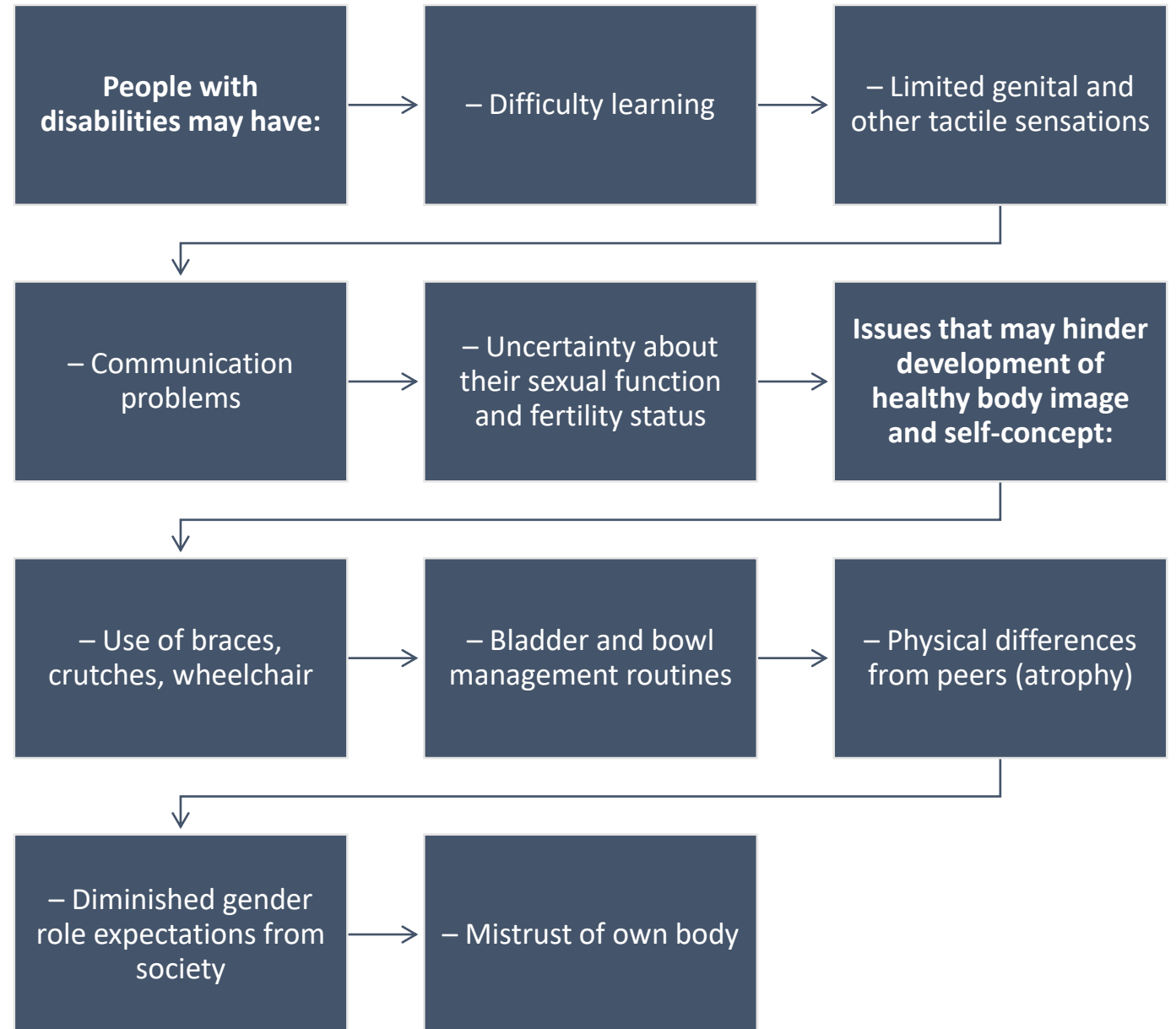


Natural Partners

- Parents
- Teachers
- Pediatricians
- Specialists
- Family
- Friends
- Behavior Specialists



CHALLENGES



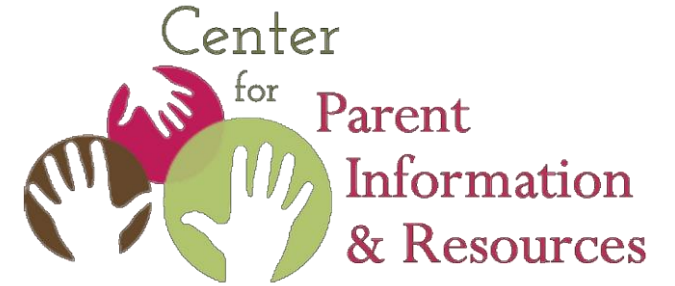
Putting Puberty and Disability in Context

[The Journey to Adulthood: What Parents Need to Know About Puberty and Sexuality](#) – Utah Parent Center



The Journey to Adulthood: What Parents Need to Know About Puberty and Sexuality

Get Information



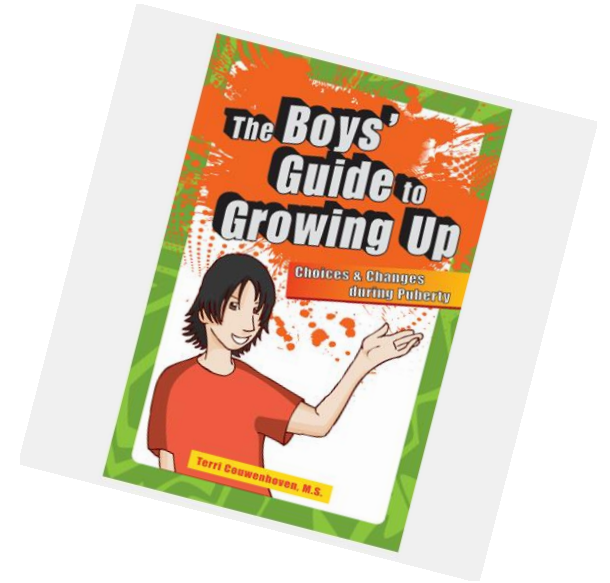
- [Human sexuality in general](#)
- [How disabilities can affect sexuality](#)
- [The special role of the parent](#)
- [The content to be taught](#)
- [Materials developed with specific disabilities in mind](#)
- [Commercial products](#)

<https://www.mysouthernhealth.com/puberty-special-needs-boys/>

<https://www.mysouthernhealth.com/puberty-special-needs-girls/>

Share Information In Advance in Meaningful Ways

- Use visuals/books/objects
- Have conversations
- Arrange time with peers
- Observe and practice
- Use coaching
- Get supplies
- Find videos
- Health exams



Repeat Information
Give "How-To" Information
Tackle mixed messages
Outwit literal thinkers
Access school resources

Discuss Puberty with Your Child who has Special Needs

- Private time. Choose a quiet time to speak with a child in private. ...
- Ask how much your child already knows. ...
- Use scientifically correct terms. ...
- It's Normal! ...
- Read a book. ...
- Explain 5 stages of puberty. ...
- The Sacred Body. ...
- Talk about inappropriate touching.

Autism

Body changes

Self-care and hygiene

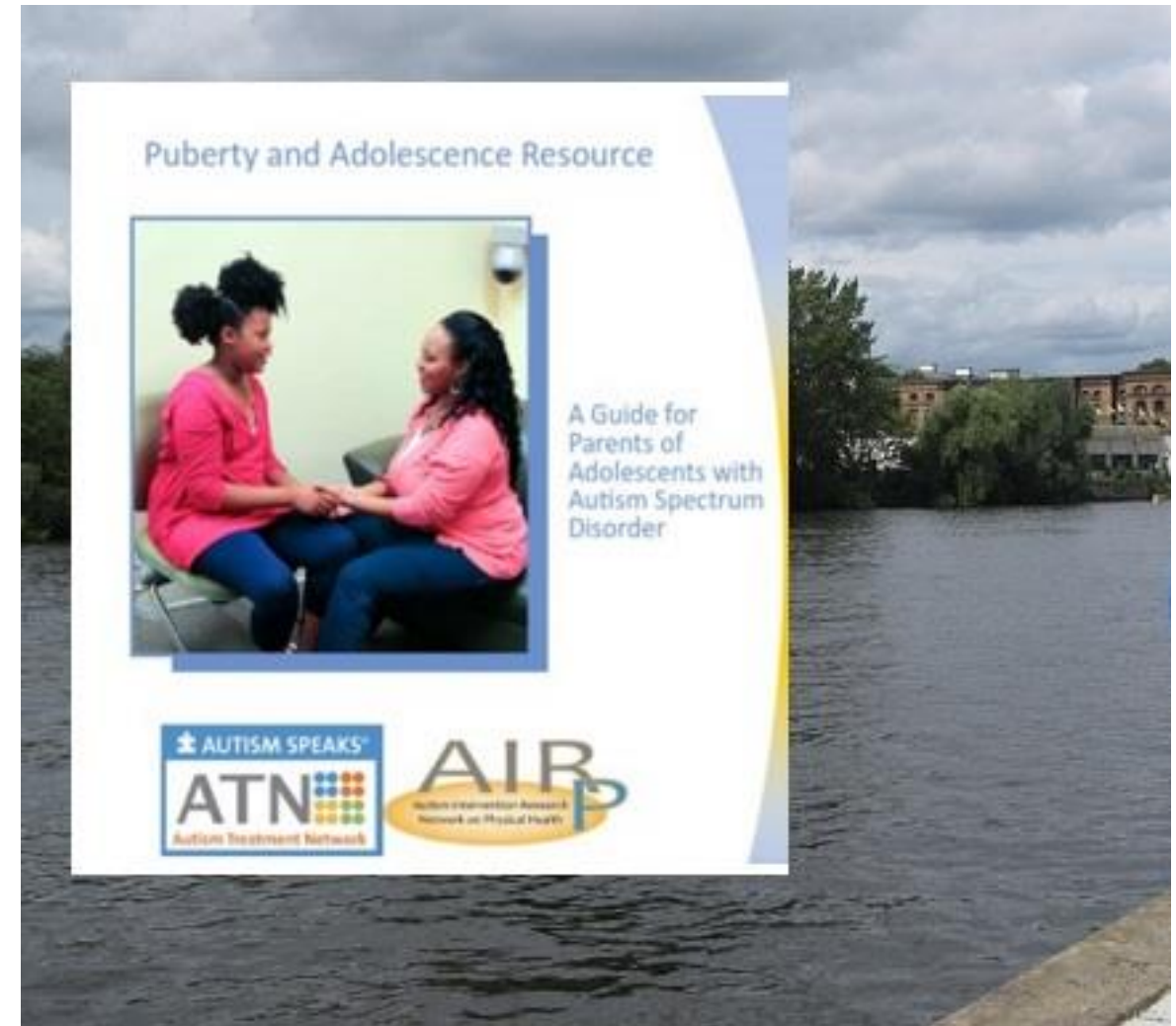
Public vs. private rules

Staying safe: Strangers, secrets
and touch

Elopement

Safety planning for increased
aggression

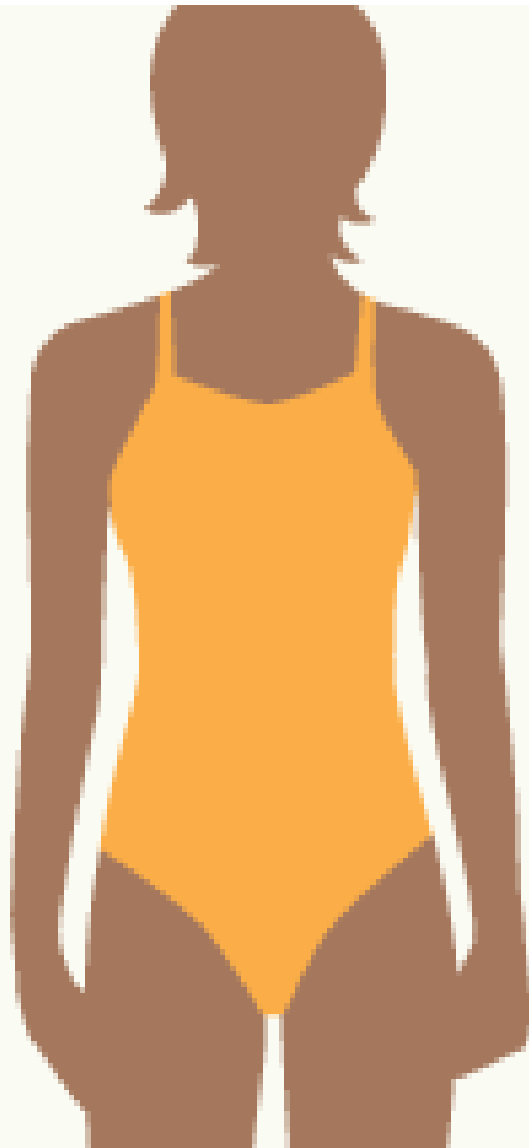
Internet safety



Face
You may get
pimples.

Sweat
Your armpits
sweat.

Menstruation
Your period
begins.

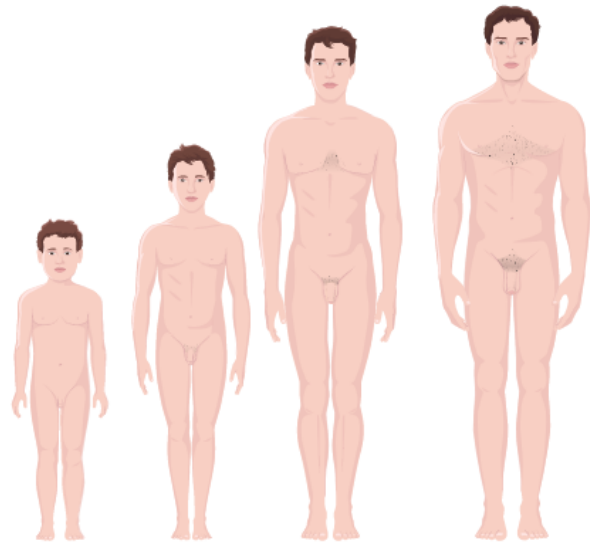


Puberty: What Happens?

Height
You get taller.

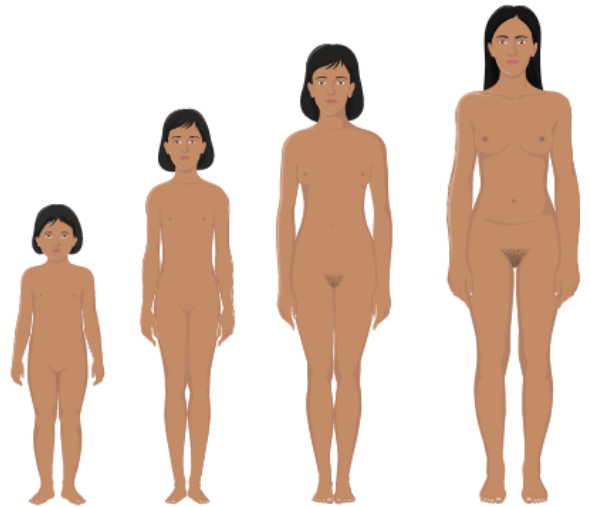
Breasts
Your breasts grow.

Hair
Hair grows in your armpits, on
your legs, and between your legs.



MALES

- Testes enlarge, testosterone produced
- Spermatogenesis stimulated
- Pubic, axillary, and facial hair begin to grow
- Increase in height



FEMALES

- Breasts enlarge
- Ovarian follicles develop
- Pubic axillary hair begins to grow
- Monthly menstrual cycle starts
- Increase in height
- Widening of hips to accommodate childbirth

Resources

- <http://www.tasccalberta.com/puberty-and-sexual-development-highrisk/>
- <https://vkc.mc.vanderbilt.edu/HealthyBodies/files/HealthyBodies-Girls-web.pdf>
- <https://vkc.mc.vanderbilt.edu/HealthyBodies/files/HealthyBodies-Boys-web.pdf>



Stopping Periods

- Periods are a normal, healthy part of being female and an important biological function, good for bone health and cardiac function. For most parents of girls with a disability periods are much easier to manage than expected and there is no reason to stop menstruation.
- If periods cause problems – severe pain, excessive bleeding or trigger seizures if your daughter has epilepsy or other issues specific to your child, talk to your GP or pediatrician about your issues and they may refer you to a gynecologist for assessment.

What About Students with Physical Disabilities?

- Although adolescents with disabilities are slower in pubertal development and more socially isolated, they are as sexually experienced as their nondisabled counterparts. Their exposure to school sex education is largely similar to that of same-age peers, yet boys with disabilities are somewhat less knowledgeable about birth control.
- Boys with severe disabilities who are sexually active are popular among their same-sex peers, much like boys without disabilities. Although adolescents with disabilities are as sexually experienced, boys and girls have less opposite-sex romantic attraction and are less sure about their sexual preference.
- Adolescents with mild disabilities have a higher tendency for same-sex attraction than do the peers without disabilities. Adolescent girls with physical disabilities consistently have higher odds of experiencing forced sex.

Cheng, M. & Udry, R. (2002)
Sexual behaviors of physically disabled adolescents in the United States. Journal of Adolescent Health.

The Role of Siblings

Sibling relationships provide an opportunity for adolescents with intellectual disabilities to learn requisite skills and appropriate behaviors through observation and experience.

Sibling relationships also socialize and prepare adolescents with intellectual disabilities for social functioning in other peer contexts, as the sibling provides opportunities to experiment with behaviors and learn from observed interactions between the typically developing sibling and others (Begum and Blacher [2011](#)).



What To Teach

- Body Image
- Self-Esteem
- Being Healthy
- Hygiene
- Puberty
- Social Skills
- Private vs. Public
- Sexual Orientation
- Menstruation
- Abuse Prevention
- Masturbation
- Relationships & Boundaries
- STDs, Birth Control, Pregnancy

Endocrine Problems in Children and Adolescents Who Have Disabilities

- Changes/differences in growth, body size, bone formation and health
- Differences in balance of salt, water, vitamins, sugar and weight
- Precocious, typical or delayed puberty
- Puberty/menstrual management
- Needed treatments for growth or endocrine balance

One Parent's Story

Increases in refusals and meltdowns

Navigate a complete change in medications

Periods that occurred 3 of 4 weeks of the month.

Respond to significant neurological changes

Teaching our child to practice good-self care during menses

Respond to periodic surges in mood

Respond to an increased interest in masturbation and kissing

Teach our child to dress differently

Giving the sex talk