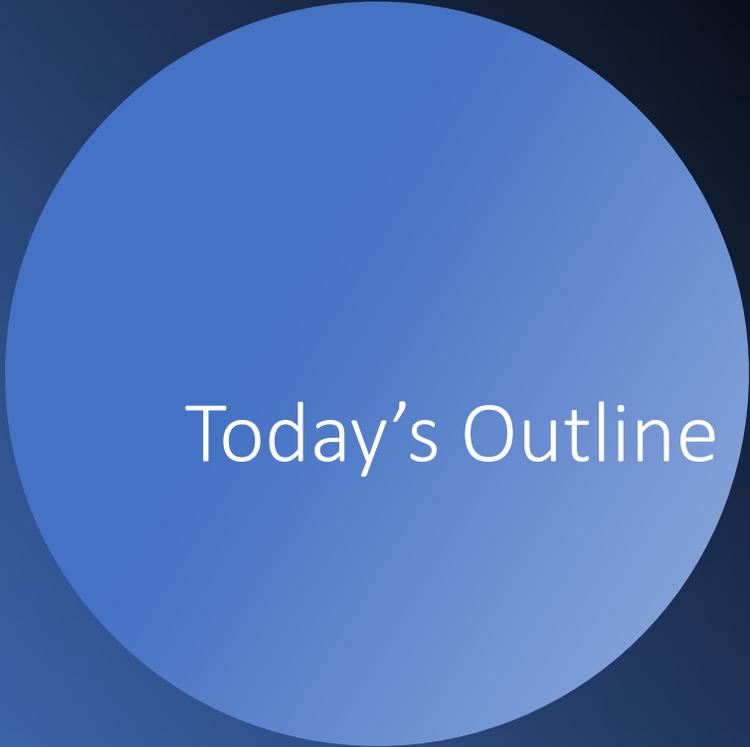


Puberty: Preparing Your Pre-Teen



Today's Outline

1. Teaching: Why, How and When
2. Parents as Teachers
3. Teaching about the Physical Changes of Puberty
4. Common Behaviors seen during Puberty
5. Medical Recommendations

Why?

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Promoting Healthy Sexuality for Children and Adolescents With Disabilities

The purpose of this article:

”to promote competence in achieving a healthy sexuality regardless of physical, cognitive or socioemotional limitations”

Amy Houtrow, MD, PhD, MPH, FAAP,^a Ellen Roy Elias, MD, FAAP, FACMG,^b Beth Ellen Davis, MD, MPH, FAAP,^c
COUNCIL ON CHILDREN WITH DISABILITIES Dennis Z. Kuo, MD, MHS, FAAP Rishi Agrawal, MD, MPH, FAAP
Lynn F. Davidson, MD, FAAP Kathryn A. Ellerbeck, MD, FAAP Jessica E.A. Foster, MD, MPH, FAAP Ellen Fremion, MD, FAAP, FACP
Mary O'Connor Leppert, MD, FAAP Barbara S. Saunders, DO, FAAP Christopher Stille, MD, MPH, FAAP
Jilda Vargus-Adams, MD, MSc, FAAP Larry Yin, MD, MSPH, FAAP Kenneth Norwood Jr, MD, FAAP Cara Coleman, JD, MPH
Marie Y. Mann, MD, MPH, FAAP Edwin Simpser, MD, FAAP Jennifer Poon, MD, FAAP Marshalyn Yeargin-Allsopp, MD, FAAP, and
Alexandra Kuznetsov



When?

Start Early! Ideally ages 8-9 years old

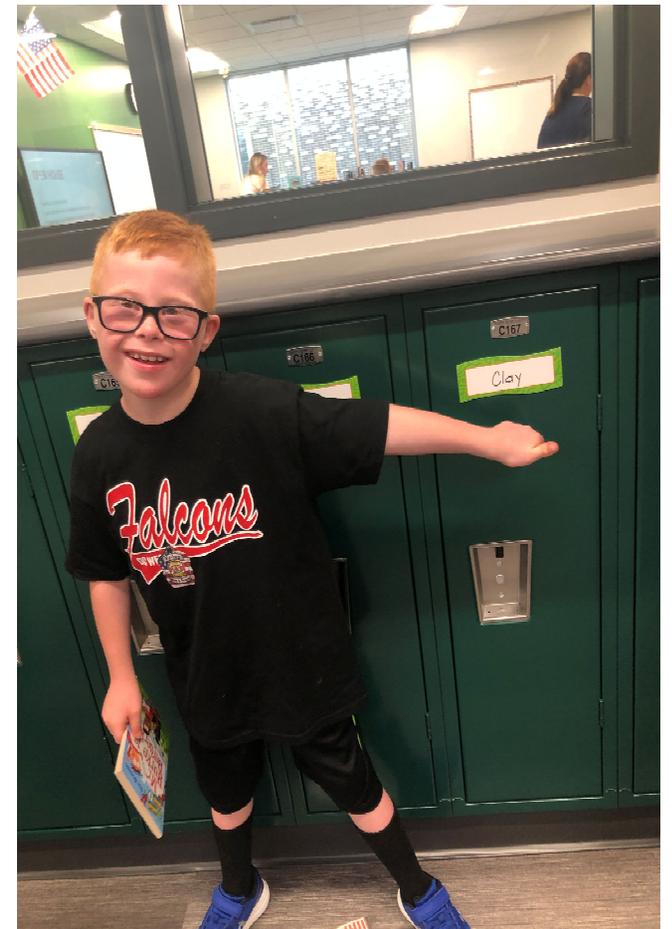
Research shows that people with disabilities receive substandard sex education and reproductive healthcare

- Less education in school, by parents and medical providers
- More influence from media
- Less opportunity socially

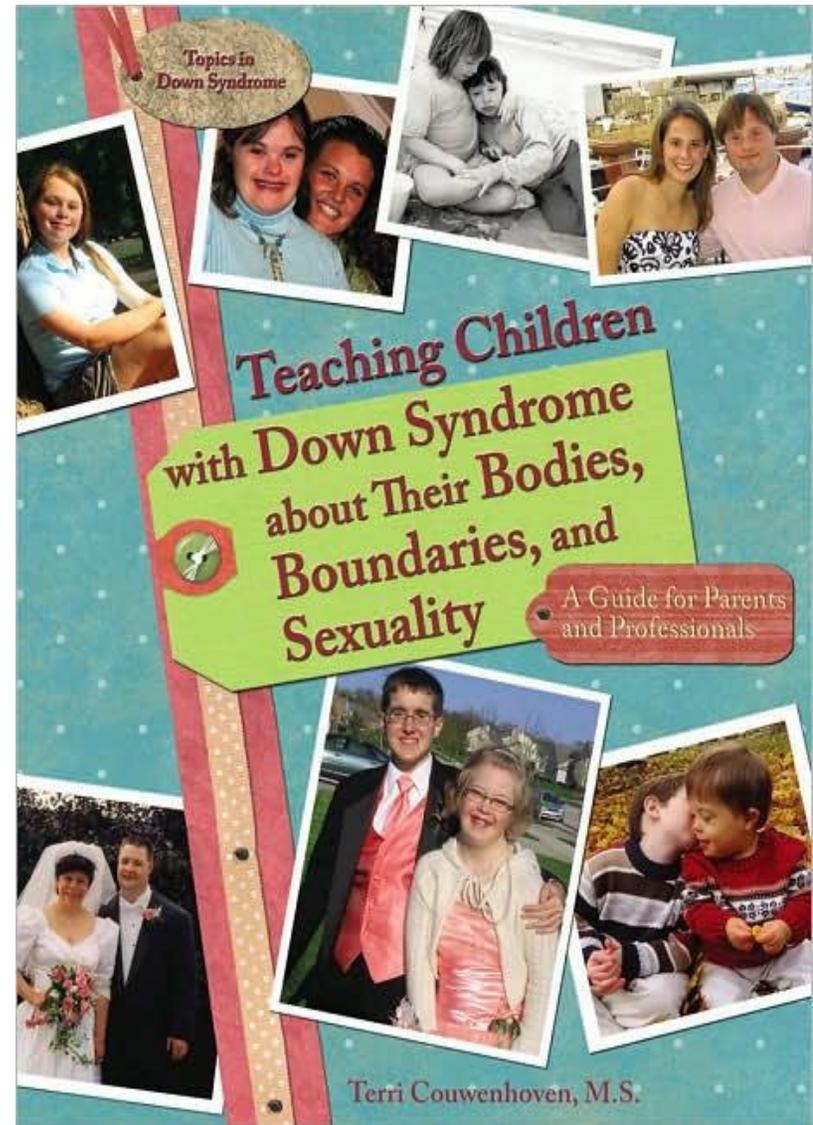
Normalized the topic!

Teaching developmentally appropriate sex education starting early in childhood helps children develop a safe, healthy and positive attitude toward themselves and others which includes understanding:
respect,
consent
relationship building.

By starting early, teaching can help youth recognize coercion and decrease the risk of abuse and can help minimized problem sexual behaviors.



How?



Quoting Terri Couvwenhoven, M.S.

Developmental
Age determines
HOW to teach.

Chronological
Age determines
WHAT to teach.

Chronological vs. Developmental

- Developmental age helps determine “how” to teach
 - Clues for adaptations/modifications of info
 - Use what you know:
 - Expressive & receptive language levels
 - Reading level
 - Communication methods (how do you check learning)
 - Receptive/expressive language ability
 - Life experiences
- Chronological age determines “what” to teach
 - What is socially appropriate for chronological age
 - Societal norms, rules and expectations
 - “Teach to conservative norm” - Hingsburger



Parents as Teachers

Use simple language

Use words they know or understand

Fewer of them

Avoid need for abstraction



Accurate
information



Understandable



Timely/Relevant



Repeat



Review



Reinforce

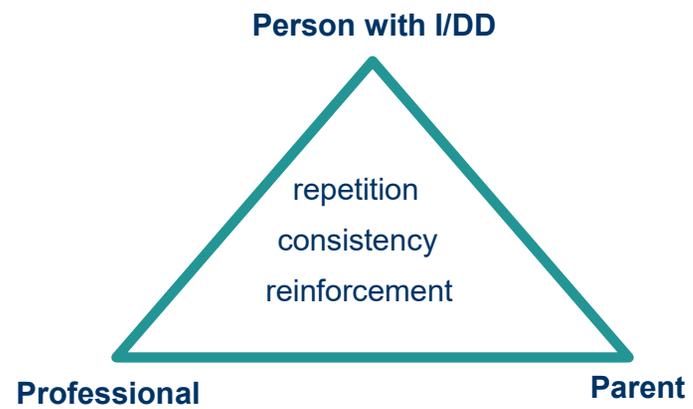
Use Multi-Sensory Approaches

- More than talking (telling). . .
 - Seeing
 - visual strategies
 - drawings
 - photos
 - demonstration
 - slides
 - diagrams
 - touching
 - models
 - dolls
 - doing
 - role play
 - dramatic play
 - real life experiences

Repetition & Reinforcement

- Use everyday moments to review and reinforce
- Real or contrived teachable moments
- think of as “process” vs. “session”
- use life transitions to introduce or review info
- look for natural infusion sites in existing activities and services

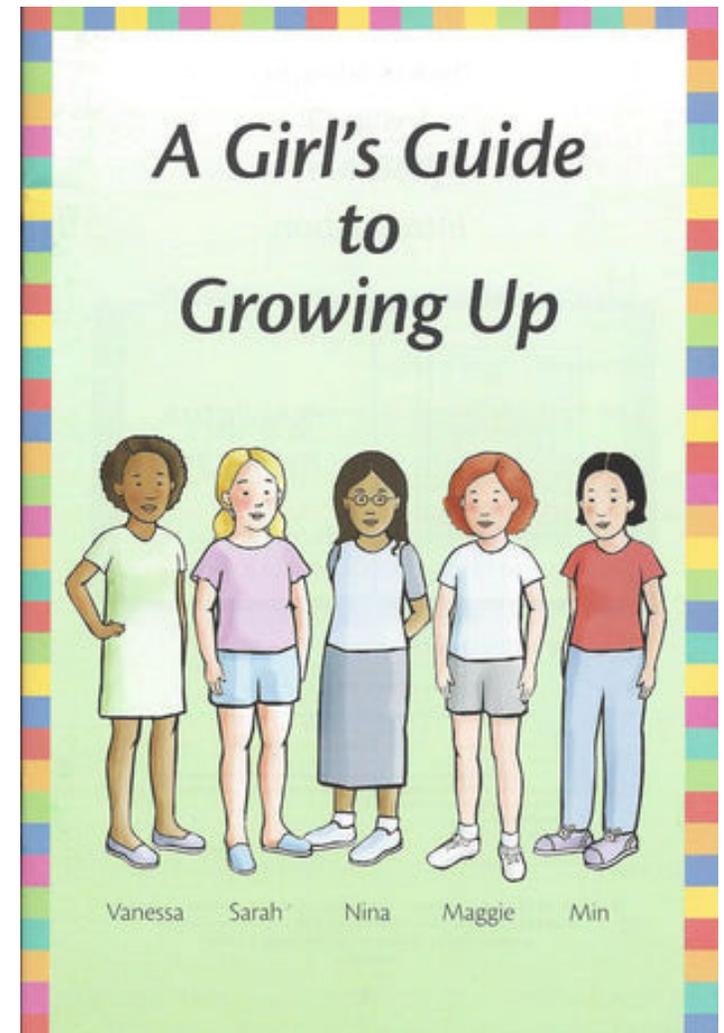
Collaboration is critical



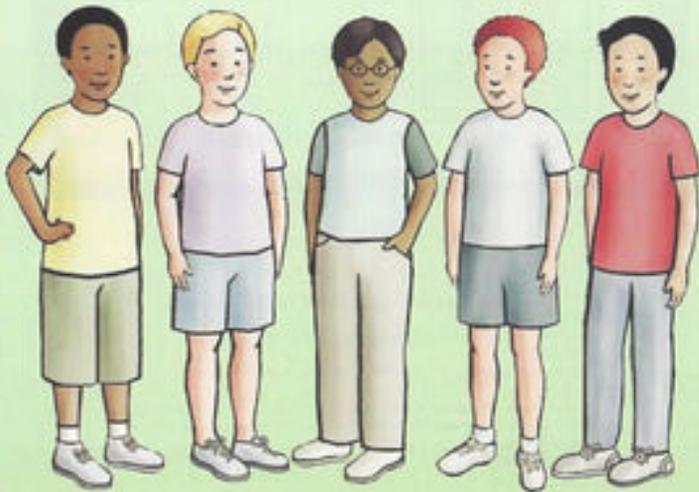
Teach accurate terms for body parts

Teach a range of vocabulary as your child gets older to prevent embarrassment by lack of understanding by peers

(including slang)



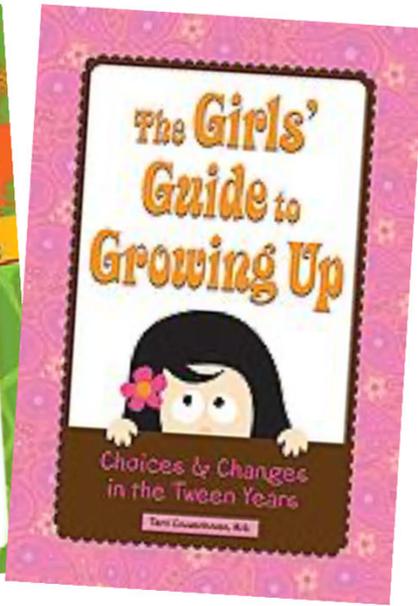
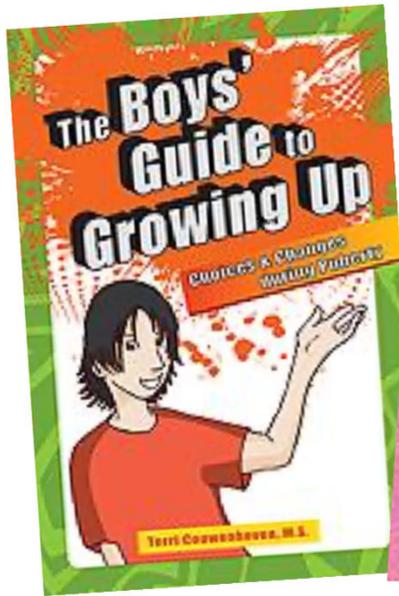
*A Boy's Guide
to
Growing Up*



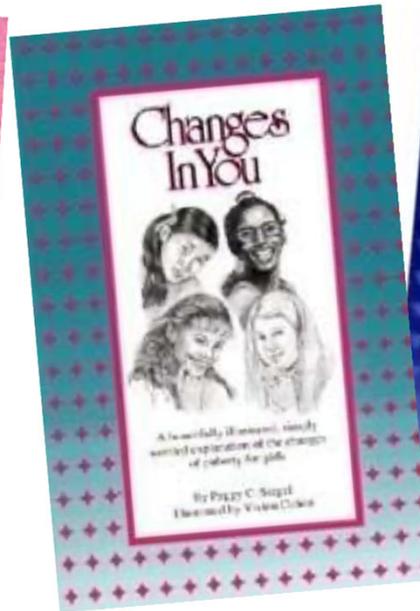
Anthony Josh Michael Tom Kevin

Terri Couwenhoven's book has very accurate drawings in Appendix A

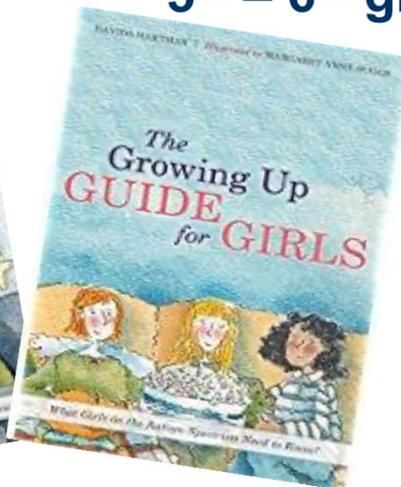
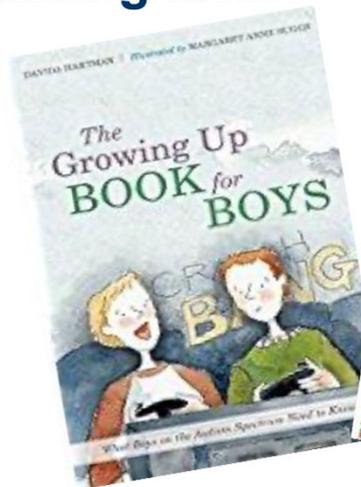
Teaching About the Body



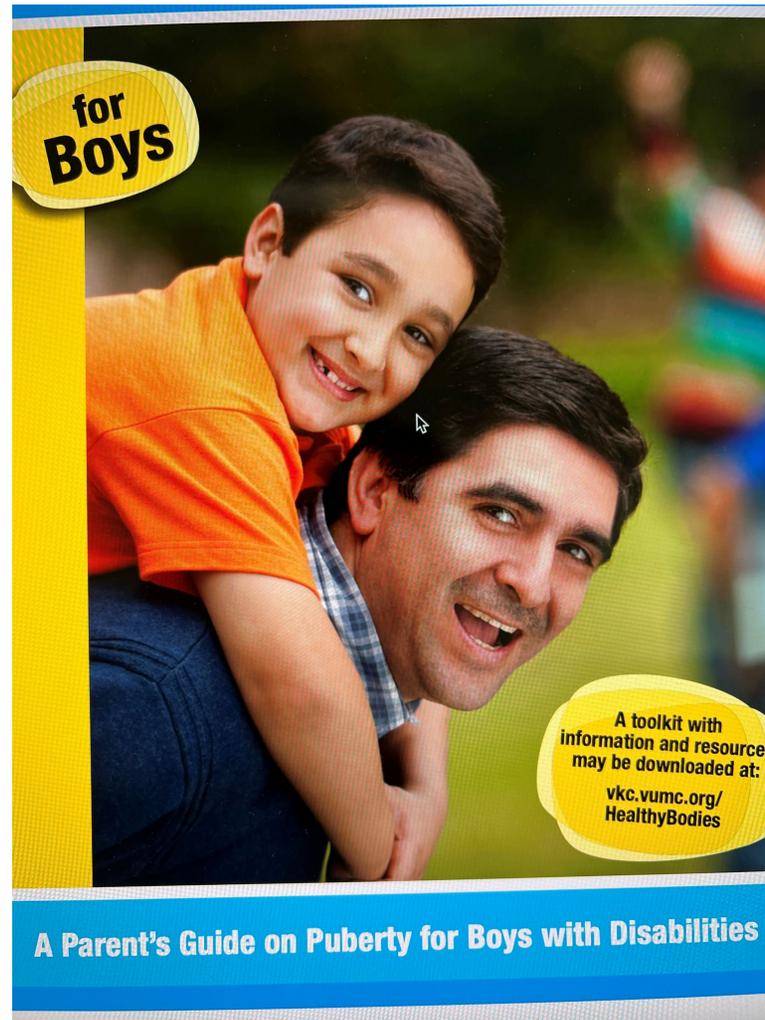
3rd Grade reading level



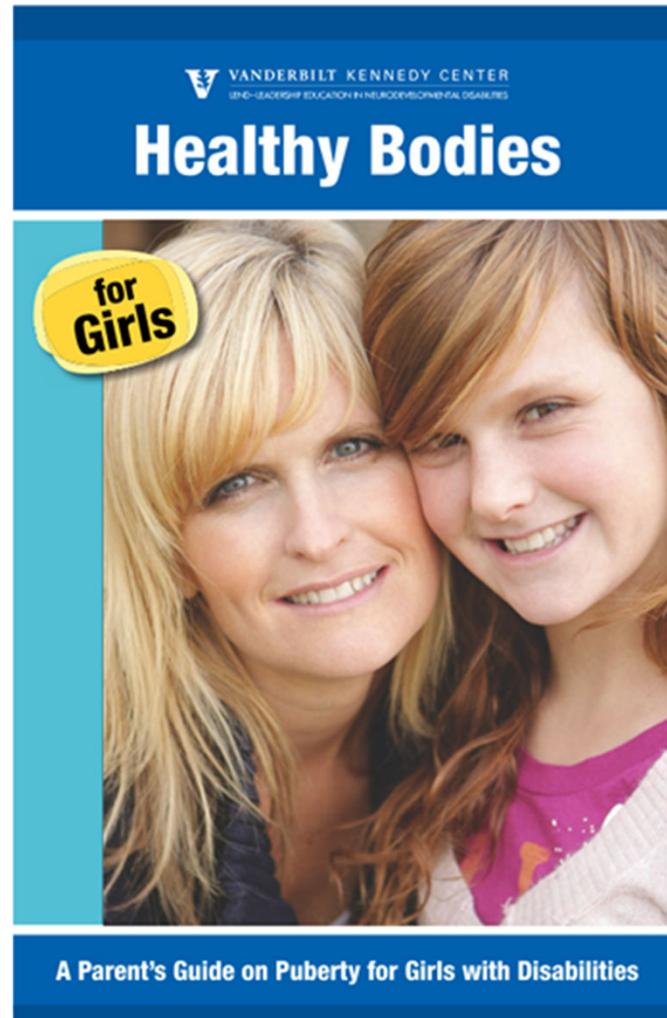
5th – 6th grade reading level



<https://vkc.vumc.org/healthybodies/files/HealthyBodiesAppendix-Boys.pdf>

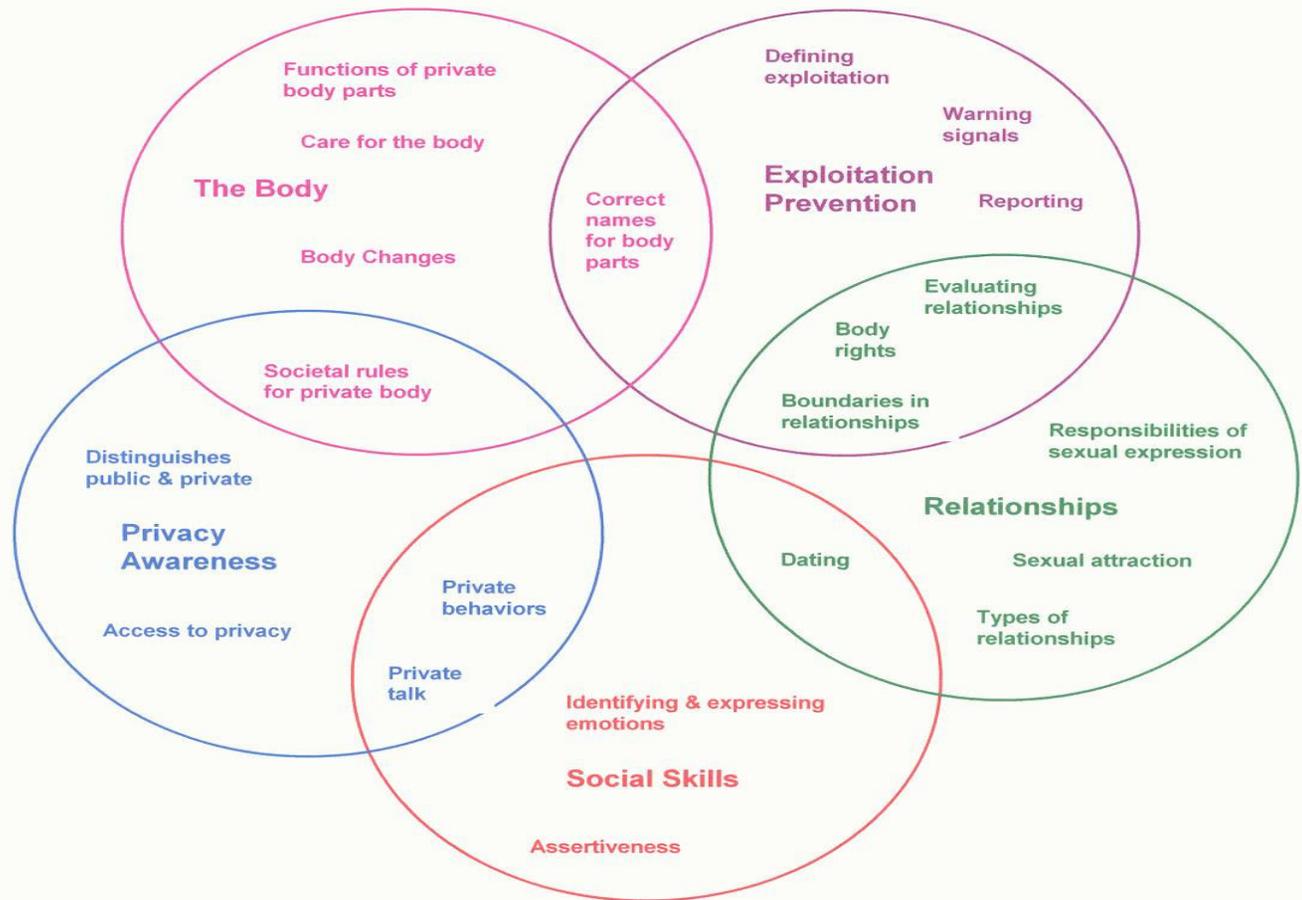


<https://vkc.vumc.org/healthybodies/files/HealthyBodies-Girls-web.pdf>



What?

- Incorporate Family Values



Teaching Children with Down syndrome About their Bodies, Boundaries, & Sexuality: A Guide for Parents & Professionals ©2007 by Terri Couwenhoven www.woodbinehouse.com

Topics to Teach:

Self care Skills

Private vs Public Body Parts

Model and Teach about Privacy at home (knock first, closing doors)

Identify the child/adolescents “private place” at home

Teach modesty / Societal Rules

Teach Public Bathroom Rules

Teach Body Rights / Personal Boundaries

Societal Rules about Private Body Parts

- This skill is an important concept to teach social rules for an individual's private body parts. (This includes rules to remember about your body)

Rules to Remember about your Private Body Parts

1. My body is my own. No one can touch my body without my permission.
2. My private body parts need to be cleaned and taken care of just like the rest of my body.
3. Private parts should be covered when I am in public places
4. If I want to touch my private parts, I should wait until I am in private.
5. I should respect other people's bodies in the same way I respect my own.

Remember to teach:

No touching other people's private parts

No staring at other people's private body parts

No talking about other people's private parts

Methods for teaching:

- Begin early with teaching a sense of responsibility
- Break down the tasks into smaller steps (enlist OT help if needed)
- Chaining – small steps are learned/linked together to complete a complex skill
- Praise! Make it fun!
- Gradually fade out / avoid teaching learned helplessness
- Gentle Persistence

Teaching Personal Boundaries

Circles[®]

Intimacy & Relationships

■ Stranger Circle

■ Wave Circle

■ Handshake Circle

■ Far Away Hug Circle

■ Hug Circle

■ Private Circle



IT'S OK TO HUG YOUR MOTHER... IT'S NOT OK TO HUG THE MAIL CARRIER.



Teaching about Physical Changes of Puberty

- Physical development and body changes in children with Down syndrome are similar to those in the general population concerning puberty.
- Ages 9-13 years old for girls
- Ages 10-14 years old for boys
- But more preparation is needed for understanding puberty and managing the changes

Use teachable moments

When you notice changes

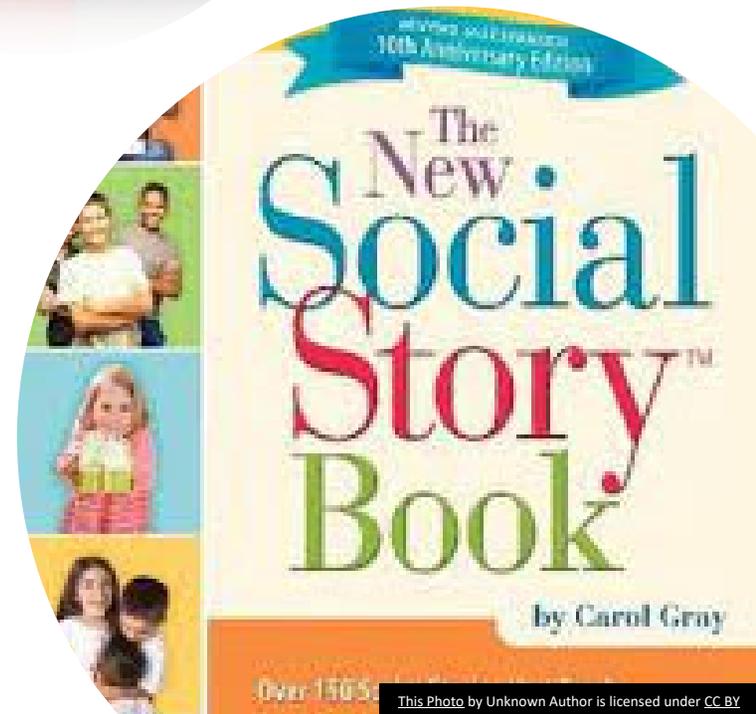
When your child points out changes

BEFORE the Human Growth and Development class at school



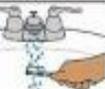
Use visuals

- Books
- Charts
- Social Stories (Carol Gray)
- Videos





I BRUSH MY TEETH

- 1 Squeeze toothpaste onto your toothbrush. 
- 2 Hold toothbrush under the tap. 
- 3 Brush your teeth. 
- 4 Spit the toothpaste into the sink. 
- 5 Rinse your mouth and smile. 

Hygiene Schedule



These are pictures for the hygiene schedule. Just laminate them, cut them out, put velcro on the back and they are ready to be attached to your schedule.



-----This is the hygiene schedule. Just laminate and put hard velcro inside each square.

The Picture Communication Symbols © 1991-2001 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission. Bender® is a trademark of Mayer-Johnson LLC.



Teaching about Periods:

Most girls do quite well with advanced preparation and using concrete teaching methods and repetition.

Video:

All Women Have Periods – An old (emphasis on old- 1979) but repetitive video that is extremely helpful for young girls with moderate to severe developmental disabilities who need concrete instruction on how to change a pad. In the video, Jill (who has Down syndrome) learns from her sister how to change a pad. It is rather poor quality but, it can be viewed at

<https://www.youtube.com/watch?v=qEx2Y5NMJHU>

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Period Panties

Period Pants 101

Everything a parent
needs to know about
period-proof underwear



Sex Ed Rescue



Thinx Inc. is on a mission to provide *every body* with better period solutions. Join the 1 million customers choosing comfier periods with Thinx.

The Guide to Good Health

for Teens & Adults
with Down Syndrome



Brian Chicoine, M.D. & Dennis McGuire, Ph.D.

Common Preteen/Teen Behaviors

- With the transition to middle school, children need age-appropriate social skills.
 - At this age, there can be more academic disparity which can make full inclusion more difficult.
 - Crushes and interest in dating begin as teens become older so teaching dating skills is important.
-
- Safe vs Unsafe Ways to Meet People
 - Recognizing Rejection
 - Red Light / Green Light – Teaching activities related to dating (Chapter 10 Terri's book)

Masturbation

Children with Down syndrome often require more time and direct instruction on privacy rules.

Allow time and space.

Self Talk

Teach self talk as a private behavior as it can be viewed negatively by the general public due to lack of understanding

Teach and Name Emotions

Childmind.org - videos on emotional health



Medical Recommendations

- Fertility: most men with Down syndrome are infertile and most women with Down syndrome are fertile. The recurrence risk for Down syndrome is 50% if a woman with Down syndrome becomes pregnant, so gyn care is important.
- Many birth controls options
- Prevention of STDs
- HPV vaccines
- Transition care - start early (GotTransition.org)
- Sex Education in schools/ exploitation prevention/ parent advocacy

Resources:

Pediatrics (2021) 148 (1): e2021052043.

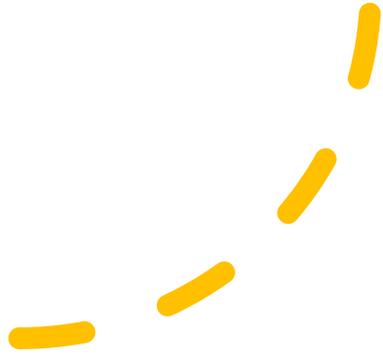
<https://doi.org/10.1542/peds.2021-052043>

Addressing Healthy Sexuality for Children and Teens with Disabilities

The American Academy of Pediatrics offers guidance on discussing and promoting sexual health for children and teenagers with disabilities in a newly published clinical report.

The report, "Promoting Healthy Sexuality for Children and Adolescents With Disabilities," published in the July 2021 *Pediatric* updates a 2006 report and recognizes the need for pediatricians to help families begin discussing sexuality early in the patient's life.

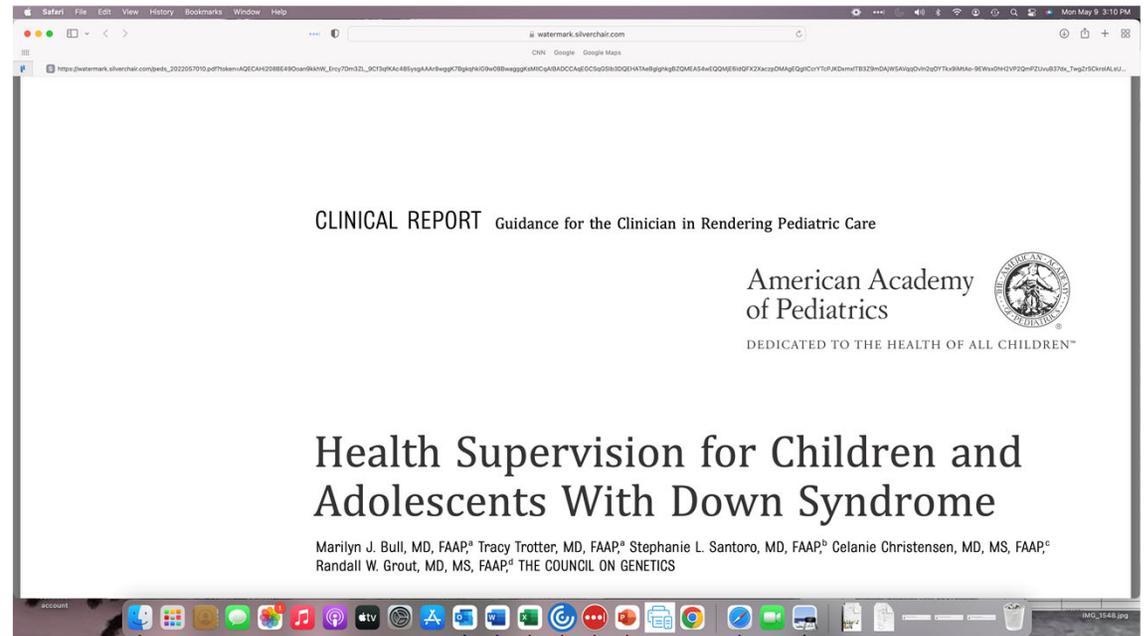


- 
- A Girl's Guide to Growing Up A video series and teaching kit designed for students with mild to moderate disabilities this resource includes teaching guide and packets of 10 student booklets. The instructional material is organized in chapter format, allowing for lesson breaks, instructional focus and revision. Topics include external anatomy, physical and emotional changes of puberty, health and hygiene and privacy and safety. Parent teaching materials are available for purchase separately. Available from <http://www.marshmedia.com/> \$
- 

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http://publications.aap.org/pediatrics/article-pdf/149/5/e2022057010/1282390/peds_2022057010.pdf

In the May 2022 issue
of Pediatrics :
Updated Guidelines for
the care of children and
adolescents with Down
syndrome





**A FAMILY TOOLKIT:
PEDIATRIC-TO-ADULT
HEALTH CARE TRANSITION**

Helpful Resources for Parents/Professionals Supporting Pre-adolescents with I/DD

A Girl's Guide to Growing Up A video series and teaching kit designed for students with mild to moderate disabilities this resource includes teaching guide and packets of 10 student booklets. The instructional material is organized in chapter format, allowing for lesson breaks, instructional focus and revision. Topics include external anatomy, physical and emotional changes of puberty, health and hygiene and privacy and safety. Parent teaching materials are available for purchase separately. Available from <http://www.marshmedia.com/> \$149.95

A Girl's Guide to Puberty & Personal Safety- This video builds on the above video but also includes information about boy's bodies, more detail on female anatomy and functions of sexual organs, a definition of sexual intercourse with an emphasis on privacy and maturity, societal behavior related to public & private, as well as safety information (touching, secrets and strangers). Teaching guides include pre- and post-test measures designed to focus on the important ideas from each chapter. Parent teaching materials are available for purchase separately. Available from <http://www.marshmedia.com/> \$149.95

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Changes in You by Peggy Siegel. Published by James Stanfield Company - \$299.00. www.stanfield.com . 800-421-6534. A visual program for teaching pre-adolescents about physical, emotional and social changes that accompany puberty. Includes laminated drawings with

optional teaching scripts on the back of each picture. Comes with teacher's guide and male and female student copies of *Changes in You* books.

First Impressions Can Make a Difference (Module 1- Hygiene)- Published by James Stanfield Company. www.stanfield.com. Includes a "how to take a shower" video using humor and exaggeration. Male and female video \$399. Grooming, dress, and attitude modules also available.

Managing Puberty, Social Challenges, and (almost) Everything- Coulter video 2013. <http://coultervideo.com/> This video, designed for females with autism, includes chapters on puberty, the body, the mind, being social, fashion sense, dating, understanding sexuality, and staying safe. Mainly a teen-aged girl "talking head" explaining concepts with some picture and mini-video examples thrown in.

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel Published by Future Horizons ISBN: 1-885477-94-5 www.futurehorizons-autism.com . This book contains already developed social stories for teaching about body changes, appropriate sexual behavior, and encouraging independence with hygiene and self care. Great ideas for creating teaching tools using Boardmaker © and Picture This © picture symbol programs.

Teaching Children with Down syndrome about their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals by Terri Couwenhoven (2007). A comprehensive "how-to teach" guide that offers practical information and ideas for addressing sexuality issues across the life span. The book includes loads of "use at home" activities that are useful for teaching about the body changes, privacy, and hygiene. Detailed and realistic drawings included in the appendices. Available at www.woodbinehouse.com

<http://kc.vanderbilt.edu/healthybodies/> - includes parental advice for education and teaching tools for sons and daughters with I/DD. Spanish page as well.

Puberty Resources Designed for Individuals with Intellectual Disabilities

The Boy's Guide to Growing Up: Choices & Changes During Puberty by Terri Couwenhoven . A book designed specifically for puberty-aged males with more moderate developmental disabilities (3rd grade reading level). Content includes information about body changes, handling sexual feelings, all with an emphasis on social appropriateness. Available at www.woodbinehouse.com or on Amazon.com

A Girl's Guide to Growing Up: Choices and Changes in the Tween Years by Terri Couwenhoven (2011). A book designed for girls with more moderate intellectual disabilities (3rd grade reading level) about changes that happen during puberty. Content addresses body changes, periods, managing menstruation, handling sexual feelings, and being social appropriate. Includes fun activities to check understanding. Available at www.woodbinehouse.com or on Amazon.com

Changes in You by Peggy Siegel.

Written specifically for girls and boys with cognitive disabilities, this book uses realistic drawings and straightforward language (5th grade reading level) to explain the physical, emotional, and social changes of puberty. Books for males and females are available for purchase separately at [Amazon.com](https://www.amazon.com)

The Growing Up Guide for Boys: What Boys on the Autism Spectrum Need to Know! By Davida Hartman (2015). A compilation of social stories related to a whole range of topics relevant to puberty. Available on Amazon.

The Growing Up Guide for Girls: What Girls on the Autism Spectrum Need to Know! By Davida Hartman (2015). A compilation of social stories related to a whole range of topics relevant to puberty. Available on Amazon.

Video self modeling- changing a pad- This web site link changes often. Google "changing a pad autism" and it usually appears. If your daughter needs a quick review for changing a pad (and she will) find this link on the web. From Hands in Autism®
https://handsinautism.iupui.edu/livingSkills_changingPad.html#.VYn9hE3bidU

Resources on Puberty for the general population that might also work for individuals w/DD:

Changing You: A Guide to Body Changes and Sexuality by Dr. Gail Saltz (2007). Using a direct approach and colorful illustrations of the body this book helps pre-adolescents understand the changes that will happen during puberty, male and female reproductive anatomy (internal and external), pregnancy and birth. Some illustrations may be confusing and abstract for pre-teens with intellectual disabilities. Available on www.amazon.com.

It's Perfectly Normal: Changing Bodies, Growing Up, Sex, and Sexual Health by Robie Harris (1996). Published by Candlewick Press ISBN: 1564021599. A comprehensive book that uses colored, animated illustrations to address male and female puberty, reproduction, birth, sexual orientation, decision making, and staying healthy. This book is a bit more advanced so parents may want to read this with their child. For sale at www.amazon.com

The Care and Keeping of You: A Body Book for Girls by Valerie Lee Schaefer (1998). Published by Pleasant Company Publications, this American Girl "head-to-toe" advice book addresses female puberty changes, hygiene issues, self esteem, fitness, sleep and emotions. Lots of colored pictures (animated) and easier text makes it fun reading for girls with lower reading levels. Includes empowering messages about the body. Available at www.americangirlstore.com

The Period Book: Everything You Don't Want to Ask but Need to Know by Karen & Jennifer Gravelle (1996). This more advanced book for females covers "changes you can see" and "changes you

can't see" but includes information on tampon use, first pelvic exams, and how to handle common problems. Available at www.amazon.com

The Period Diaries (on youtube.com)- This series of videos is archived on YouTube from the www.beinggirl.com web site. Designed for puberty-aged, typically developing females who are about to, or already have their periods, the videos address numerous topics. These short videos are *fast moving* and don't always provide visuals to illustrate what Sarah (the main character) is discussing but for *some girls* these *might* work. Episode 3- Protect those panties, illustrates how to insert a pad into panties and can reinforce the importance of pad usage. Other episodes include:

Episode 1- Period 101
Episode 2- Know your cycle
Episode 3- Protect those panties (using a pad)
Episode 4- Pads vs. liners
Episode 5- Fact or fiction
Episode 6- Acne
And more.....

Period Underwear Products

Period Underwear- Use these instead of pad or tampons or as back up to prevent accidents. These products are designed to catch menstrual flow *without pads or tampons*.

Thinx brand- <https://www.shethinx.com/products/hiphugger-panties>

Modibodi brand- available on Amazon.

Knixteen Underwear are designed to prevent leaks and unwanted smells *while using menstrual products*. Think of them as a backup in case of accidents <https://www.knixteen.com/pages/how-it-works>

Lunapads underwear with removable inserts. www.lunapads.com

Dear Kates- Dear Kate underwear and apparel are include a wick away lining to absorb fluids in case of accidents. www.DearKates.com

Apps

Flo Period Tracker- Helps you remember your last period and when your next one is due. Accurately and reliably helps predict menstruation, log symptoms, and flow.

Clue- Period and ovulation tracking app. Requires inputting of data.



Thank you!