



## **BODIES, BOUNDARIES, AND PUBERTY: PUBESCENCE IN MALES WITH I/DD**

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# USE PUBESCENCE TO SET THE STAGE...

- Normalization of sexuality
- Maturity & changing expectations
- Approachability
- Shifting of Power
  - Choice making
  - Assertiveness

# 5 TOP FAQ'S

- Timing
- Comprehension
- Independence with self care
- Social inappropriateness
- Safety

# TIMING- PHYSICAL DEVELOPMENT






- no significant differences in puberty onset
- wide variations in all individuals with and without DS
- average onset (general population):
  - 9-13 in girls (before age 8 see physician)
  - 10-14 in males (before age 9 see physician)
  - onset earlier in African Americans/Hispanics

# COMMON EARLY SIGNS

## Male

- Enlargement of testes and scrotum
- height spurt
- increases in fat & muscle
- areola increases in size and darkens
- pubic hair

# TANNER STAGES

Tanner stage	Male genital appearance	Male genital description
1		Testicular volume <3ml
2		Testicular volume <3ml, change in texture to scrotal skin
3		Increase in size of penis with further testicular enlargement
4		Further enlargement of penis and testicles with development of glans penis
5		Adult size and shape

# TIMING- WHEN DO I BEGIN TEACHING?

- School – HG & D
- You notice changes
- Your child notices changes
- Siblings
- Personalized, contrived teachable moments

# IMPROVING COMPREHENSION

- involve as many senses in learning as possible
- simple, direct, concrete language
- repetition & reinforcement of information over time
- Relevancy- Early education (3 S's)
  - **S**ocial Appropriateness
  - **S**afety
  - **S**elf Care



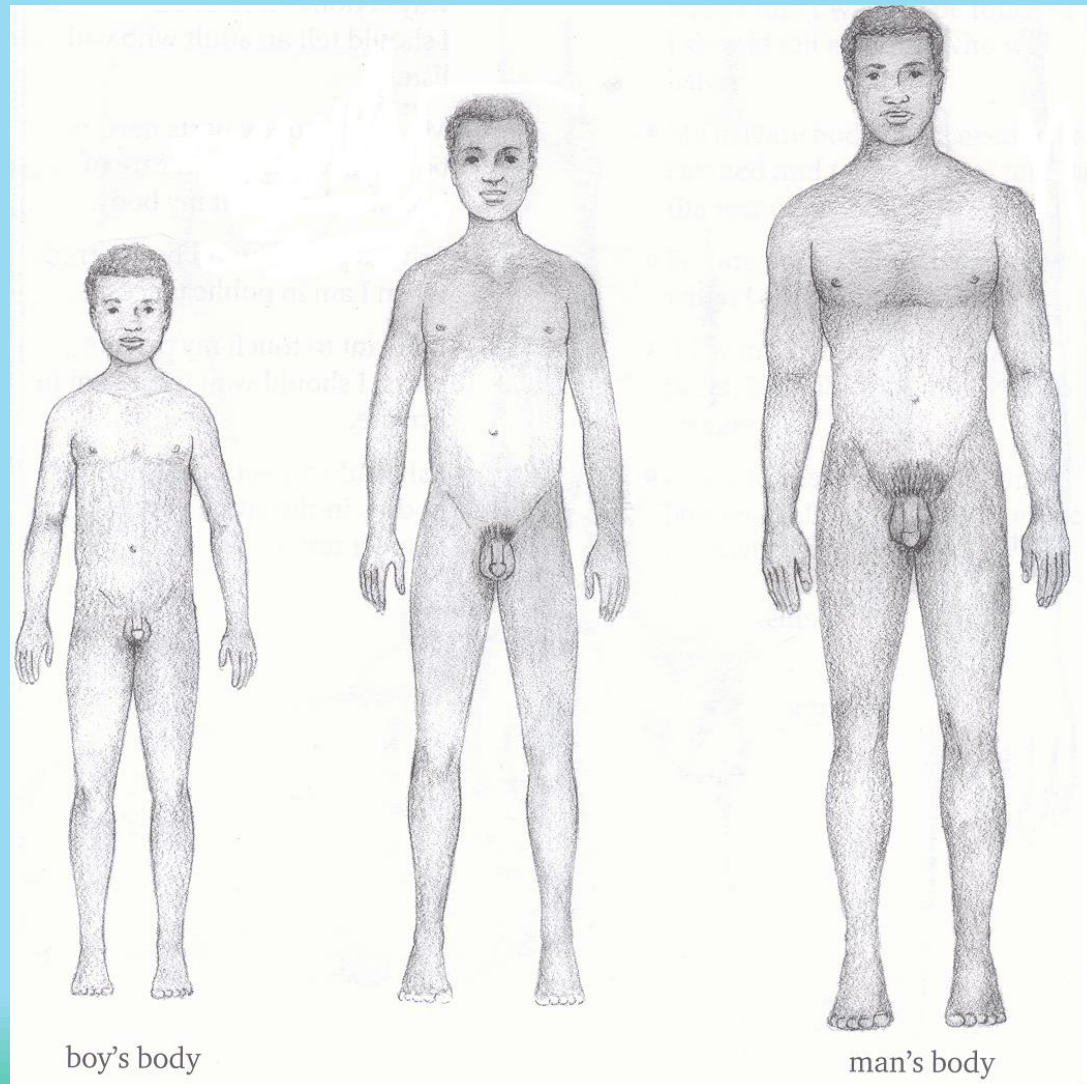
# USE CLEAR, DIRECT LANGUAGE:

“ you are at the age when your body is starting to change from a kid body to grown up body..”

“ These body changes happen to all kids during this time”..

“ this time in your life is called Puberty..

# with visuals...



# NARROW THE SCOPE & SEQUENCE

- Most important information first- Provide context

- What is puberty?

- What will I see?

- What will I feel?



Growing up!

- Self Care

- “Part of growing up is learning how to take care of your body”

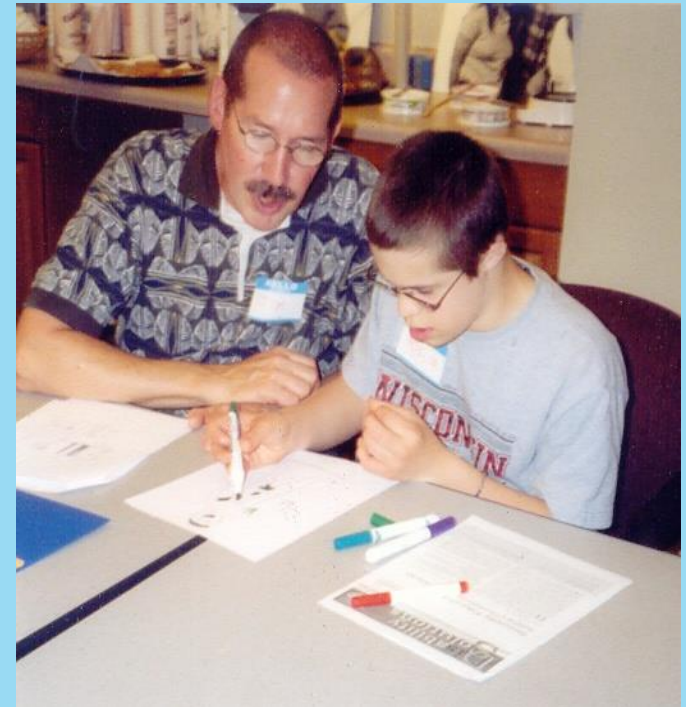
- Safety

- body autonomy - “my body is mine”

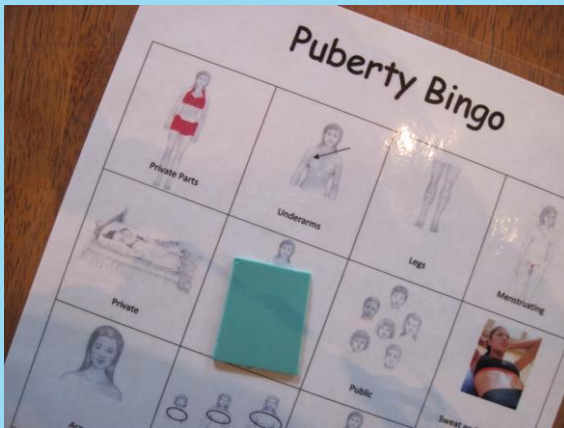
- rules for their body & private parts

- Respecting rights of others

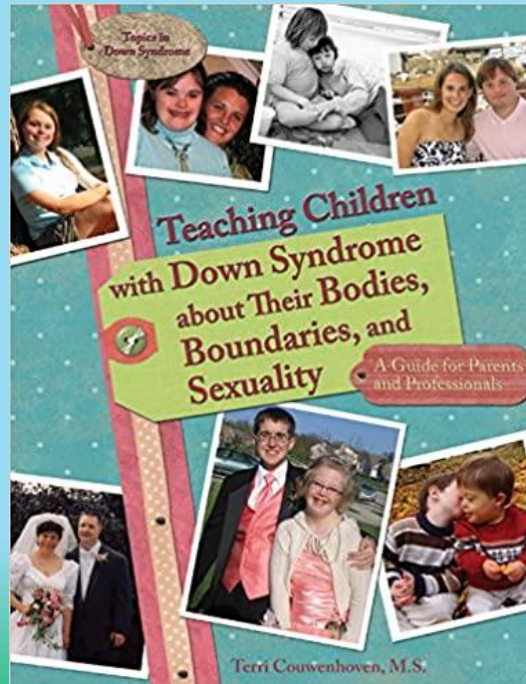
# ACTIVITY IDEAS



Boy to Man



Puberty Bingo



# INDEPENDENCE WITH SELF CARE

Bathing & hygiene

Handling erections

Managing sexual feelings

# TEACHING SELF CARE

- start with tasks your child struggles with
- break those tasks into small pieces
- teach through visuals, modeling or demonstration
- practice with supervision
- gradually fade out
- gentle persistence



# TEACHING & DEVELOPING SKILLS



Puberty bag

Story About Grooming/Hygiene for Boys

<p>It is important for me to take care of my body.</p>	<p>Taking care of my body will help me feel good about myself!</p>	<p>I need to do the following to take care of my body.</p>	<p>Wash my face.</p>	<p>Brush my teeth.</p>
<p>Wash my hair.</p>	<p>Wash my body.</p>	<p>Brush my hair.</p>	<p>Put on deodorant.</p>	<p>Cut my nails.</p>
<p>I may want to shave my face. It is ok to ask for help.</p>	<p>It is also important for me to take care of my clothing.</p>	<p>My clothes should not be dirty.</p>	<p>My clothing should not smell.</p>	<p>If I have any questions, I can ask my mom or dad.</p>
<p>People will want to be around me if I take care of myself.</p>				

<https://adsresources.advocatehealth.com/>

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- “How to take a shower” Autism Pennsylvania

Hygiene Checklist

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Remember to ask all 45 pins on each step							
brush teeth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
wash face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
get dressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
brush hair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# COMMON BARRIERS TO SELF CARE

Health issues (talk to physician)

Challenging sensory issues

Inconsistent expectations (confusion)

Unrealistic expectations (doomed to fail)

Forget to fade out (learned helplessness)

WHAT IS THE BARRIER???

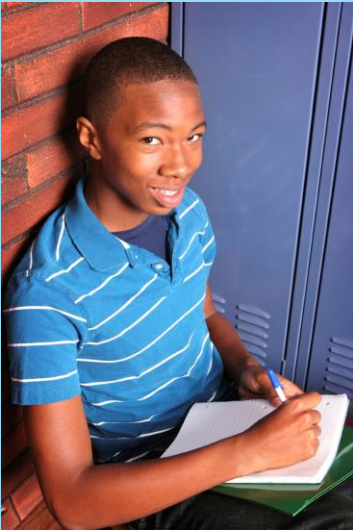


# RESPECTFUL SUPPORT (HINGSBURGER)

- Ask permission before moving into a person's private space
- wait for response (verbal or physical)
- describe what you are doing- this invites and creates openness
- encourage as much participation as possible (least restrictive prompt hierarchy)

# HANDLING ERECTIONS IN PUBLIC

- Erections are *normal*, but *private*
- If you get an erection in public you can:



Cover with books or backpack

Try to think about other things

Don't panic- an erection WILL go away after a few minutes

# SOCIAL INAPPROPRIATENESS

- Escalation of sexual feelings common (and normal) during this time
- Lack of information can lead to....
  - touching others inappropriately
  - lack of modesty with touch, talk, and behavior
  - overt crushes/sexual attraction
  - masturbation in public
  - boundary confusion
- Infantilization of people of I/DD
- Sexual behavior is still “behavior”

# MASTURBATION - WHAT'S NORMAL?

## Preadolescence & Adolescence

- Occurs with increased frequency
- private nature of masturbation understood
- enhanced awareness of unique responses to touch and self-stimulation (erotic potential)
- sexual fantasy emerges as a component of masturbation
- can be increased anxiety regarding “normalness” of behavior

# TEACH PRIVACY.. AT HOME



Private means..



My private place at home is...

- define private
- identify their private place
- teach privacy rules
  - Closing their door
  - Teach knocking & listening
- model respect for their privacy and expect the same
- teach behaviors that are private
- intentionally model modesty

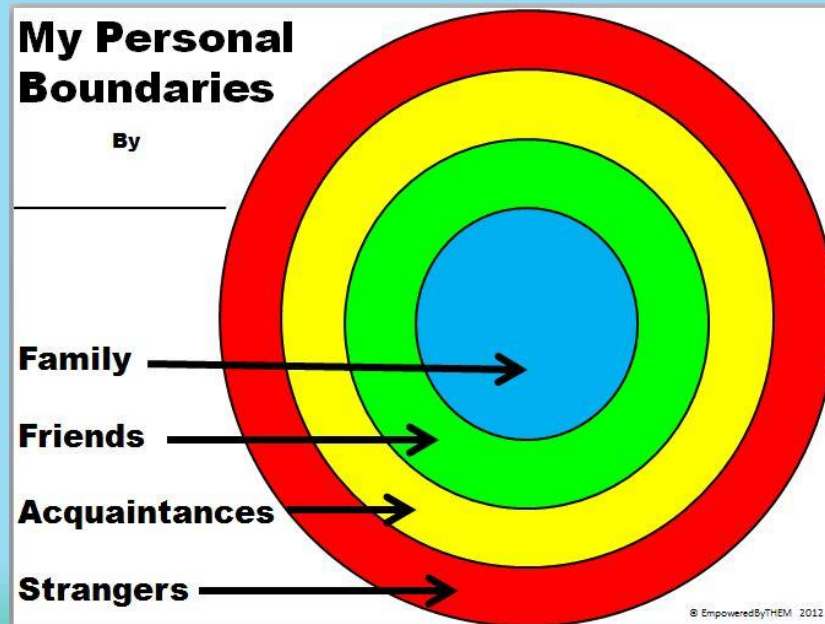
# SEX EDUCATION FOR PEOPLE WITH I/DD

FACTS/ EXPLANATION	BOUNDARIES/ SOCIAL RULES
<p>Penis, vulva, butt, breasts are <i>private body parts</i></p>	<ul style="list-style-type: none"><li>- private body parts need to be covered in public places, public rooms</li><li>- if you want to look at or touch your penis/vulva you need to be in your private place at home.</li><li>-Your private place is _____.</li></ul>
<p>Those feelings you get when you are around someone you really, really like (or have a crush on) are called <i>sexual feelings</i></p>	<ul style="list-style-type: none"><li>-Sexual feelings are normal, we all have them</li><li>-At your age you can...</li><li>-When you are dating someone, it is healthy and normal to talk about how you feel.</li></ul>
<p>Touching or rubbing my private parts can feel good. This is called <i>masturbation</i></p>	<ul style="list-style-type: none"><li>- Masturbation is private</li><li>- Masturbation is okay if I am at home in my private place.</li></ul>

# TEACH RELATIONSHIPS..THEN BOUNDARIES

PEOPLE IN MY LIFE

MY FAMILY 
MY FRIENDS 
SWEETHEART 
PAID HELPERS 
AQUAINTANCE 



# SEXUAL BEHAVIOR IS UNACCEPTABLE:

If it is nonconsensual/unwanted

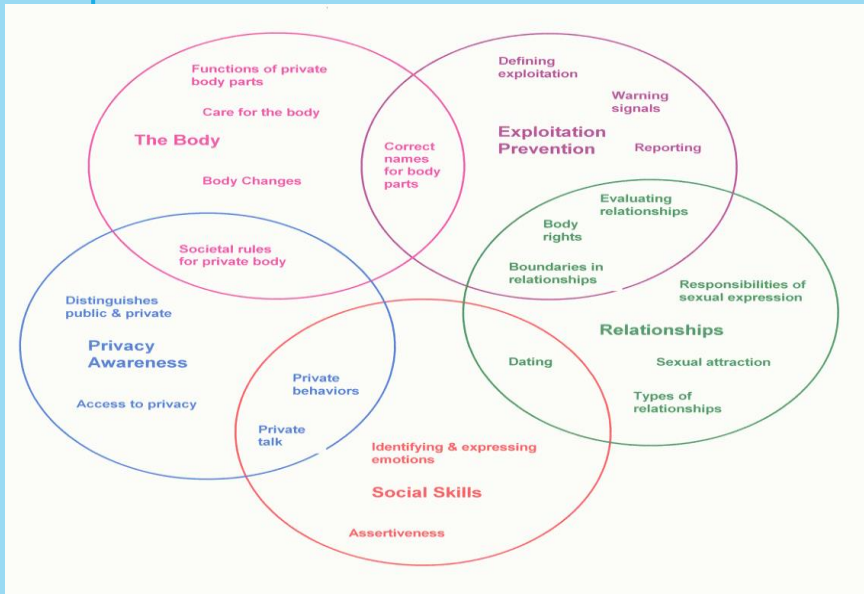
It is illegal

harmful to self or others





# EXPLOITATION



- Exploitation rates much higher in DD population
- puberty = reproduction
- Medical interventions do not prevent exploitation
- Sexuality education that includes safety and exploitation prevention information still necessary

# TEACH...

Body autonomy

Real words for private body parts

Rules for looking and touching private parts

What to do if rules are broken

- Refuse
- Leave if you can
- **TELL!!!**

# RULES FOR PRIVATE BODY PARTS



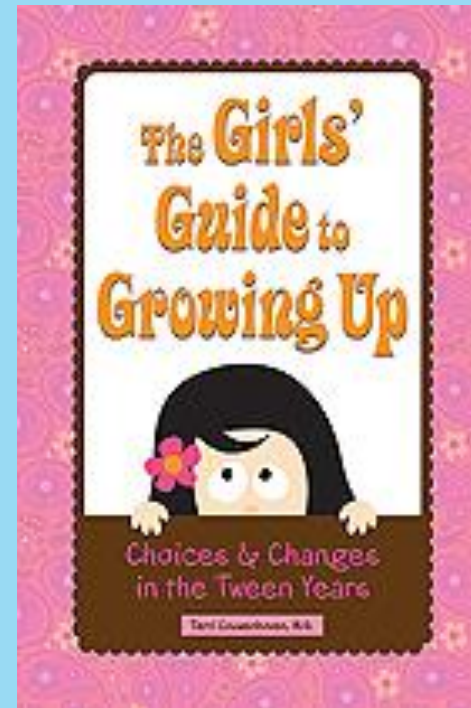
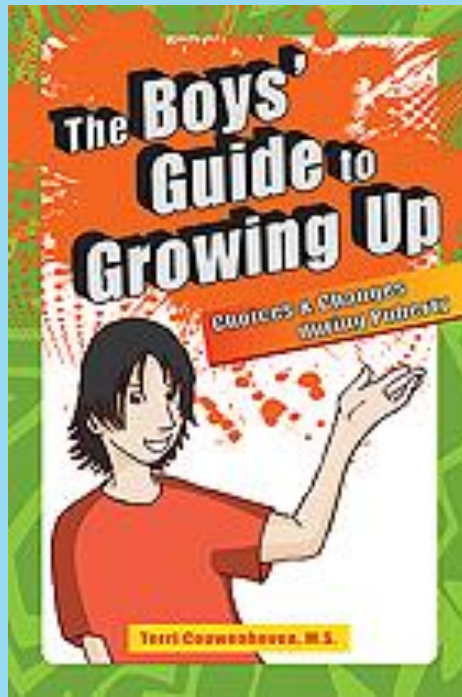
**Hygiene (only if we need help)**



**Health**



**Consensual touching in dating relationships**



**3<sup>rd</sup> Grade reading level**

**Puberty, Self Care, Social Rules, Safety**

# IN SUMMARY

- Parents- primary sex educators
- Same needs, different approaches
- Advanced preparation, teaching, are essential.
- Information is power!



# Q & A