



## PUBERTY: TOP 5 ISSUES AND CONCERNS

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## INTRODUCTION

- 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

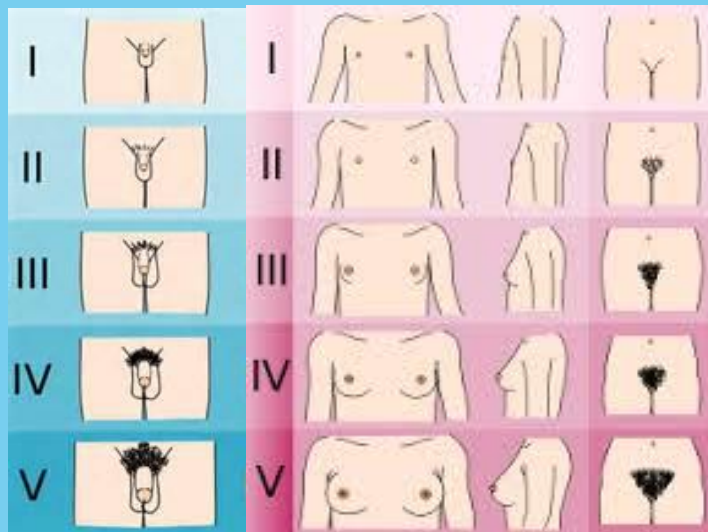
### Female

- breast budding
- areola increases in size and darkens
- pubic hair
- height increases
- increases in fat

### Male

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

## TANNER STAGES



## PARENTHOOD- IS IT POSSIBLE?

FEMALES - TRISOMY 21	OUTCOMES
26 Women (28 pregnancies)	10 normal 10 Down syndrome 1 set premature, nonviable normal twins 3 malformed 1 slight microcephaly 1 stillborn 2 aborted, no other info

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## TIMING- WHEN DO I BEGIN TEACHING?

- Human Growth & Development
- Personalized teachable moments
  - You notice changes
  - Your child points out changes
- Favorite multi-year shows
- Siblings

## COMPREHENSION

- visuals are necessary
- simple unsophisticated language
- repetition & reinforcement of information over time
- Initially, focus on the important stuff

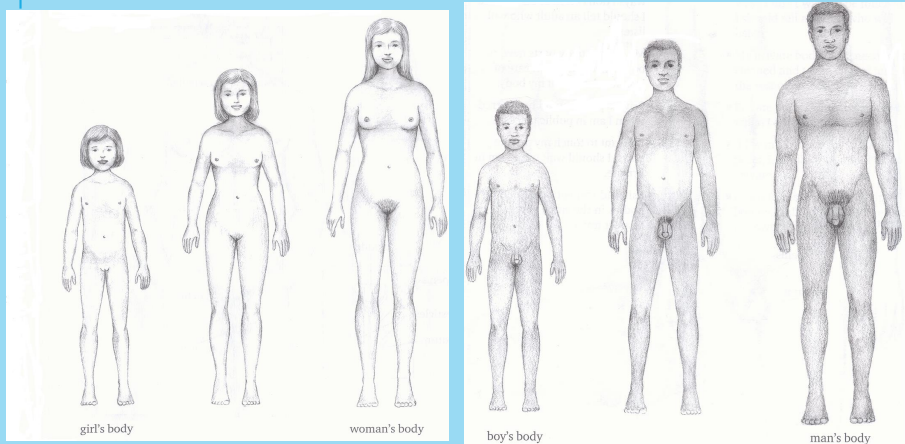
## SIMPLE VERBAL EXPLANATIONS:

“ 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 is called Puberty..

with visuals...

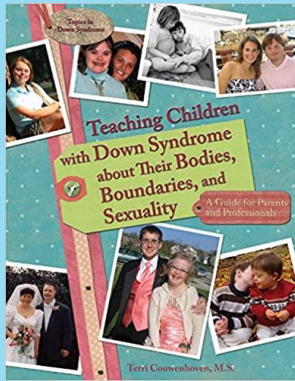


## NARROW THE SCOPE & SEQUENCE

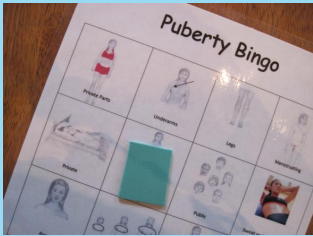
Most important information first

- What is puberty?
- what body changes to expect
- handling those changes
- privacy- what is it? How do I access it?
- rules for their body
- respecting rights of others

# EXPERIENTIAL LEARNING



Boy to Man



Puberty Bingo



Puberty bag

# INDEPENDENCE WITH SELF CARE

- Bathing & hygiene
- correctly using a pad
- handling erections
- Handling sexual feelings

# TEACHING SELF CARE

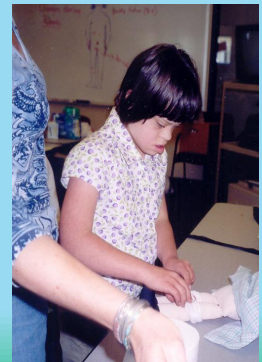
- start with tasks your child struggles with
- break those tasks into small pieces
- teach through visuals, modeling or demonstration
- practice with supervision
- gradually fade out
- gentle persistence



# MENSTRUATION & PAD USE

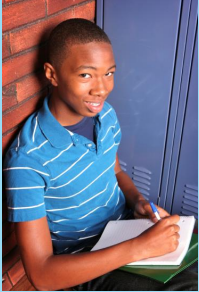
Most girls with mild-moderate I/DD do quite well with:

- Advanced preparation
- Concrete teaching
- Repetition and reinforcement
- Moms frequently surprised at how well they do
- Intermittent episodes of difficulty
- “teaching a pad autism”



## HANDLING ERECTIONS IN PUBLIC

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



get to class, sit down



Try to think about other things

Cover with books or backpack

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

## 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)

# SOCIAL INAPPROPRIATENESS

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

# TEACH PRIVACY.. AT HOME



Private means..

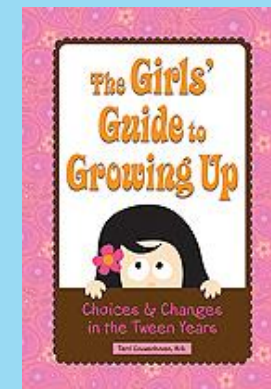
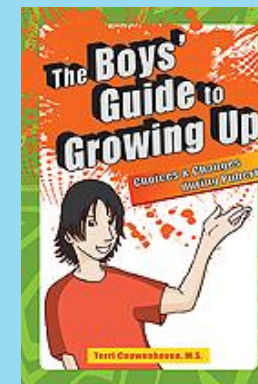
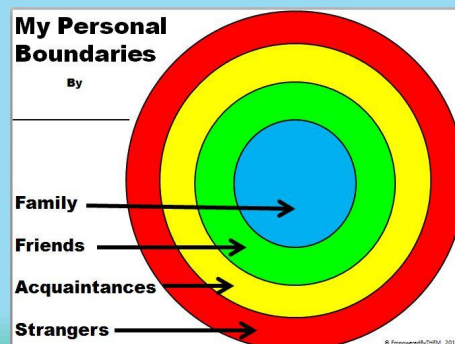
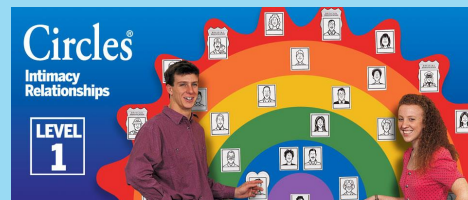


My private place at home is...

- 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
- teach & model modesty

# RELATIONSHIPS & BOUNDARIES TEACHING

PEOPLE IN MY LIFE	
MY FAMILY	
MY FRIENDS	
SWEETHEART	
PAID HELPERS	
ACQUAINTANCE	



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

<https://www.facebook.com/adultdownsyndromecenter/videos/10155386416123576/>  
Adult Down Syndrome Clinic

Puberty, Self Care, Social Rules, Safety

## 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
- escalation of anxiety & fear around this time
- Medical interventions do not prevent exploitation
- Sexuality education that includes safety and exploitation prevention information still necessary

## TEACH...

Names of private body parts

Rules for looking and touching private parts

What to do if rules are broken

- Refusal
- Leave
- Report

## RULES FOR PRIVATE BODY PARTS



Hygiene (only if we need help)



Health



Consensual touching in dating relationships



What is the *relationship* you have with the person?  
What is the *reason* for the touch?

## IN SUMMARY

- Same issues, different approaches
- Advanced preparation, teaching, are essential.
- Information is power!