

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

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# USE PUBESCENCE TO SET THE STAGE...

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

# 5 TOP FAQ'S

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

# TIMING- PHYSICAL DEVELOPMENT

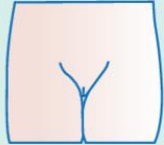
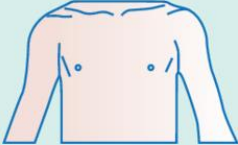

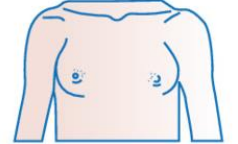
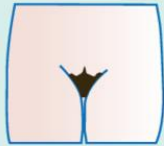
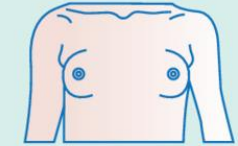

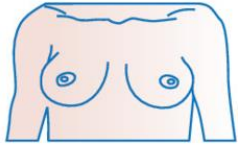


- no significant differences in puberty onset
- wide variations in all individuals with and without DS
- average onset (general population):
  - 9-13 in girls (before age 8 see physician)
  - 10-14 in males (before age 9 see physician)
  - onset earlier in African Americans/Hispanics

# COMMON EARLY SIGNS

## Female

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

# TANNER STAGES - FEMALE

Female pubic hair appearance	Pubic hair description	Breast appearance	Breast description
	No pubic hair		Elevation of papilla only
	Sparse growth chiefly along the labia/base of penis		Breast bud stage
	Darker, coarser, more curled hair		Enlargement of breast and areola
	Adult type hair over a smaller area		Projection of the areola and papilla
	Spread to the medial surface of the thighs		Recession of the areola to the contour of the breast, projection of papilla only

# TIMING- WHEN DO I BEGIN TEACHING?

- School – HG & D
- Your child notices changes
- You notice 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
- prioritize based on relevancy- Early education (3 S's)
  - **S**ocial Appropriateness
  - **S**afety
  - **S**elf Care



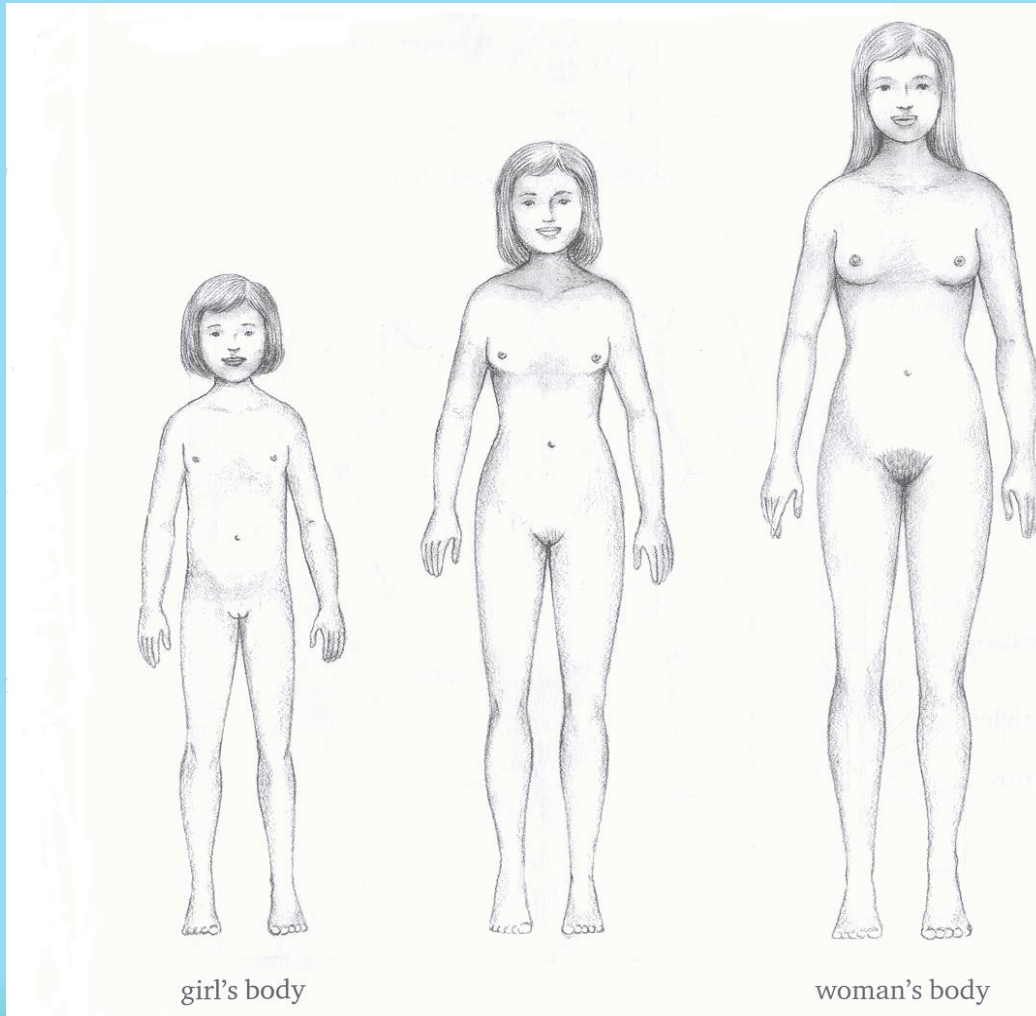
# USE CLEAR, DIRECT LANGUAGE:

“ 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

# INDEPENDENCE WITH SELF CARE

Bathing & hygiene

Managing menstruation

# 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



- “How to take a shower” Autism Pennsylvania

# TEACHING & DEVELOPING SKILLS



Puberty bag

**Hygiene Checklist**

Remember to tick off as you do each one!

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
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 STRUGGLES RE: 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 MODEL (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)



# MENSTRUATION

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

- Advanced preparation
- Concrete instruction
- Repetition and reinforcement over time
- Moms frequently surprised at how well they do
- intermittent episodes of difficulty common
- [Thinx.com](http://Thinx.com)



# TEACHING ABOUT MENSTRUATION

- Modeling pad use before puberty
- Low literacy books
- videos
  - “changing a pad autism”
- Practice periods
  - Buying
  - Feeling pads
    - Opening
    - Finding sticky part
  - Wearing (desensitization)



# HAVE A “PERIOD” PLAN

Spare clothes and supplies at school

Teach modesty with pads and supplies (private)

Designated helper- who can help?

- At home
- At school

## Getting my Period: What’s the Plan?

It is hard to know when your first period will come so having a plan can help you be prepared. Talk with your parent so you can decide together how to manage your first period.

### If I get my period at school:

If I get my first period at school, I will need to put a pad in my underwear so blood does not get on my clothes.



At school I can keep spare clothes and pads in \_\_\_\_\_ so I will have them if I need them.

Getting a period is private but if I need help I can talk to \_\_\_\_\_ or \_\_\_\_\_ at school.

### If I get my period at home:

If I get my first period at home, I will need to put a pad in my underwear so blood does not get on my clothes.



At home, I can find pads in \_\_\_\_\_ when I need them.

Getting a period is private but if I need help I can talk to \_\_\_\_\_ or \_\_\_\_\_ at home.

Remember, getting a period is normal and happens to all girls. No matter where I am when I get my first period, I will know what to do.

# WHEN THERE ARE DIFFICULTIES. . .

Physicians use least restrictive approaches to medical interventions

- minimizing risks for patients
- maximizing self determination

Least to most restrictive

- individualized instruction/teaching



- hormonal methods (i.e: OC's, Depo)



- surgical interventions (endometrial ablation, removal of reproductive organs)

# MENSTRUAL SUPPRESSION OR ELIMINATION

- Challenging behaviors (cyclical) that jeopardize the individuals safety/safety of others
- health conditions exacerbated by hormonal cycle (seizures, diabetes)
- presence of gynecological conditions that have been unresponsive to other less invasive tx's
- difficulties managing menstruation even with good training & support
- informed choice by patient

# SOCIAL INAPPROPRIATENESS

- Escalation of sexual feelings common (and normal) during this time
- Lack of information, however 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

# HANDLING SEXUAL FEELINGS IN PRIVATE

When alone and in private some people like to touch or rub their private parts when they have sexual feelings

this should only be done in your private place at home

What is your private place?



**Private means you are by yourself and nobody can see you**



# 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

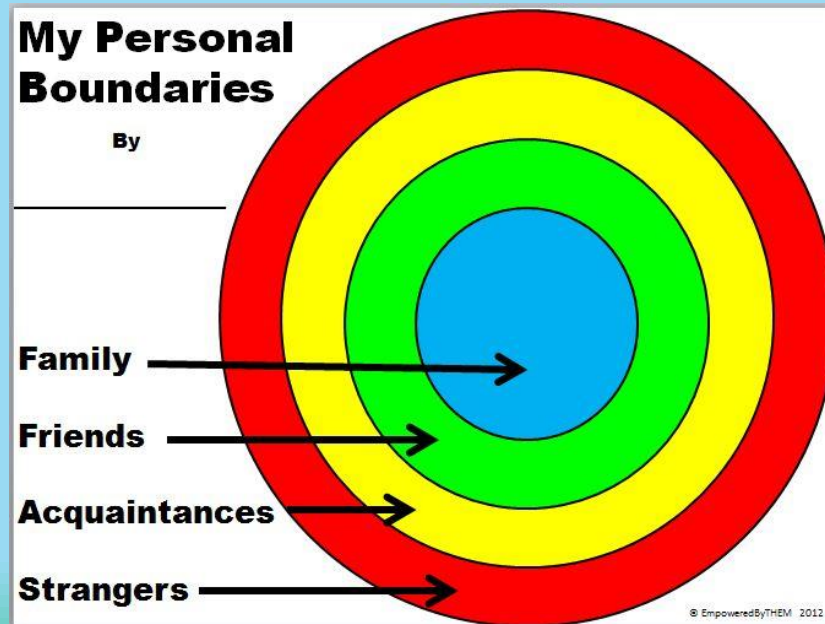
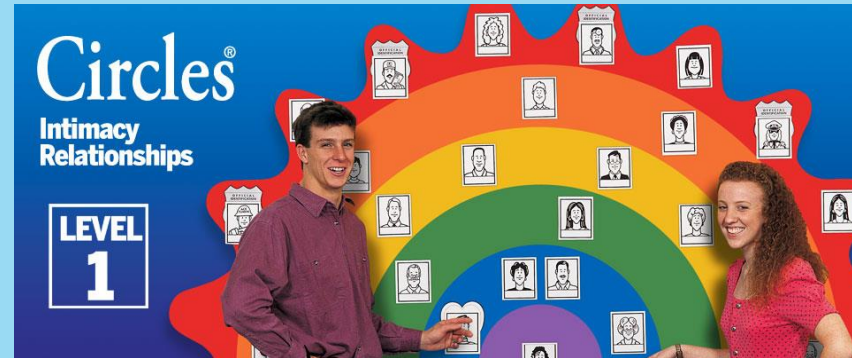
# SEX EDUCATION FOR PEOPLE WITH I/DD

FACTS/ EXPLANATION	BOUNDARIES/ SOCIAL RULES
<p>Penis, vulva, butt, breasts are private body parts</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>Once a month blood from inside your body will come out from an opening between your legs. This is called having a <i>period</i>.</p>	<ul style="list-style-type: none"><li>- periods are private</li><li>- if you need help you can talk to _____ at school and _____ at home</li></ul>

# TEACH RELATIONSHIPS..THEN BOUNDARIES

PEOPLE IN MY LIFE

MY FAMILY 
MY FRIENDS 
SWEETHEART 
PAID HELPERS 
AQUAINTANCE 





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

# SEXUAL BEHAVIOR IS UNACCEPTABLE:

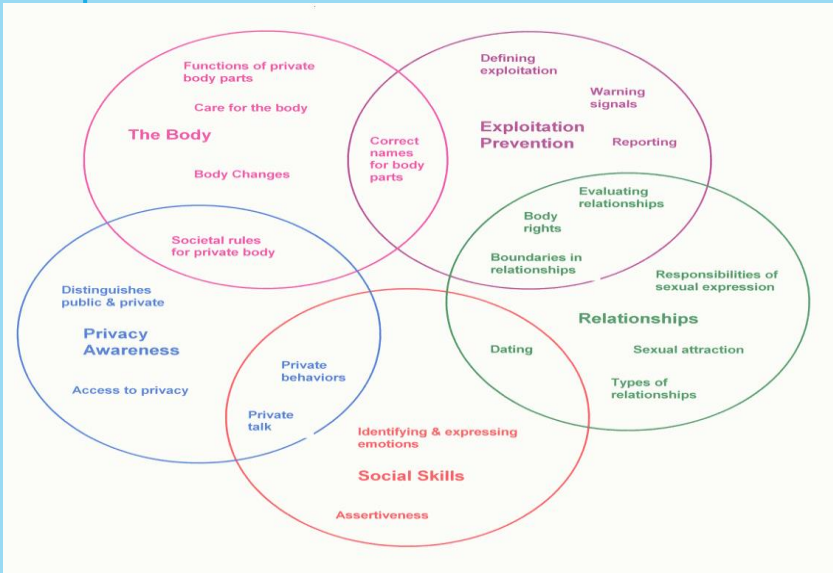
If it is nonconsensual/unwanted

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- Safety plan

- Refusal
- Leave if you can
- TELL

# RULES FOR PRIVATE BODY PARTS



Hygiene (only if we need help)

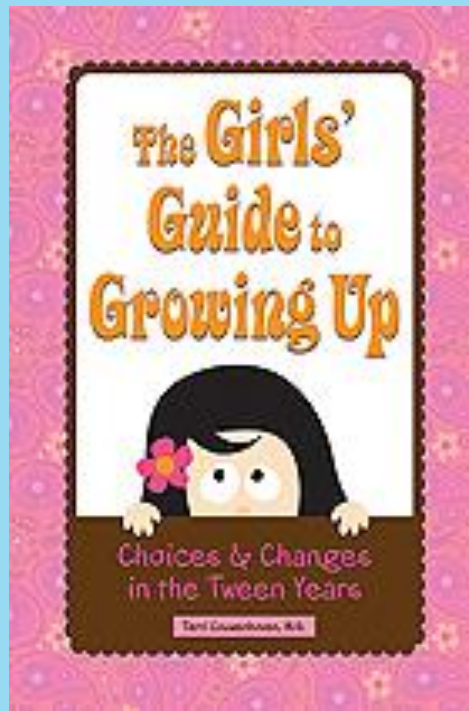


Health



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