



**The Birds
and the Bees
and Down Syndrome**



Amy Allison
Executive Director
The Farmer's House

Whoa!

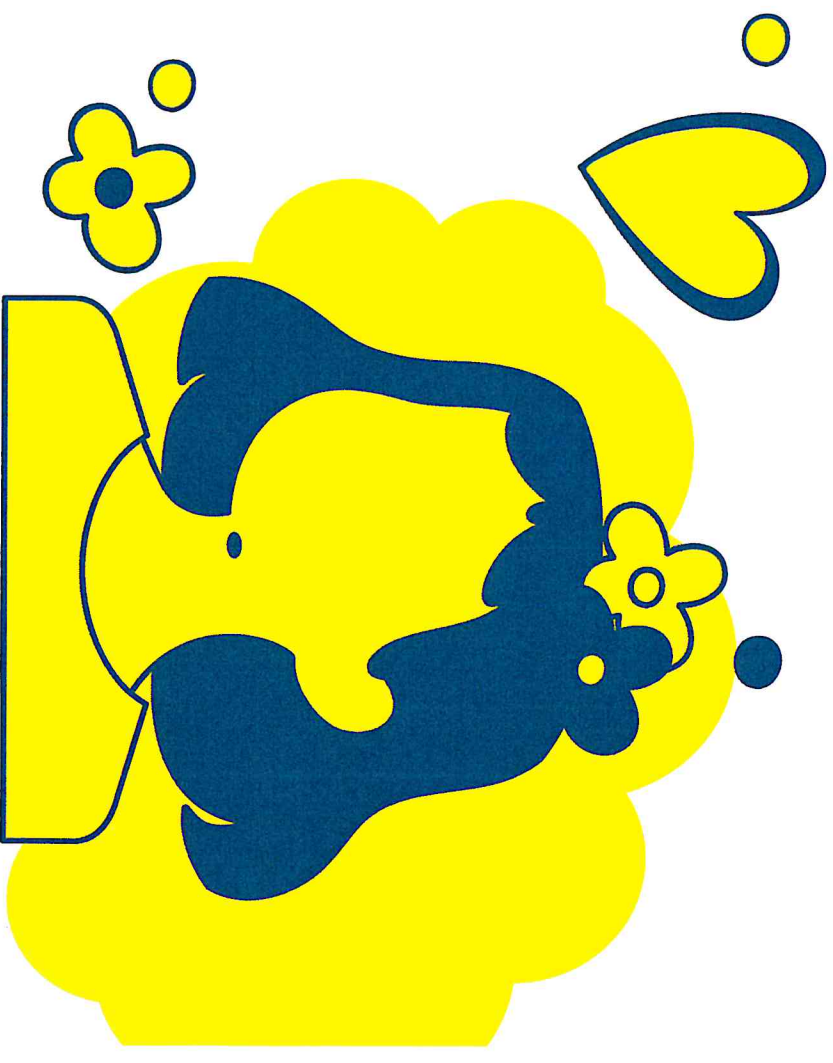
This can be overwhelming.


I don't want to do this.

I'm not ready!

Where do I start?

If not you, then who?





All people with disabilities have the right to explore and understand their bodies and sexuality in a positive and proactive manner.

#knowledgeispower



What do we mean when we say sexuality?



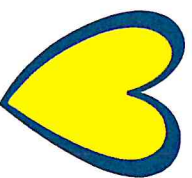
Pleasure

Boundaries

Sexual Identity

Consent

Relationships



Self-Care

Love

Development

Romance



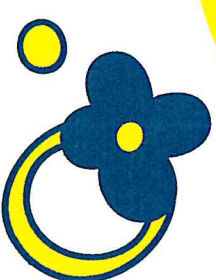
Education

Gender Identity





**What happens if we
don't talk about this?**



Misinformation

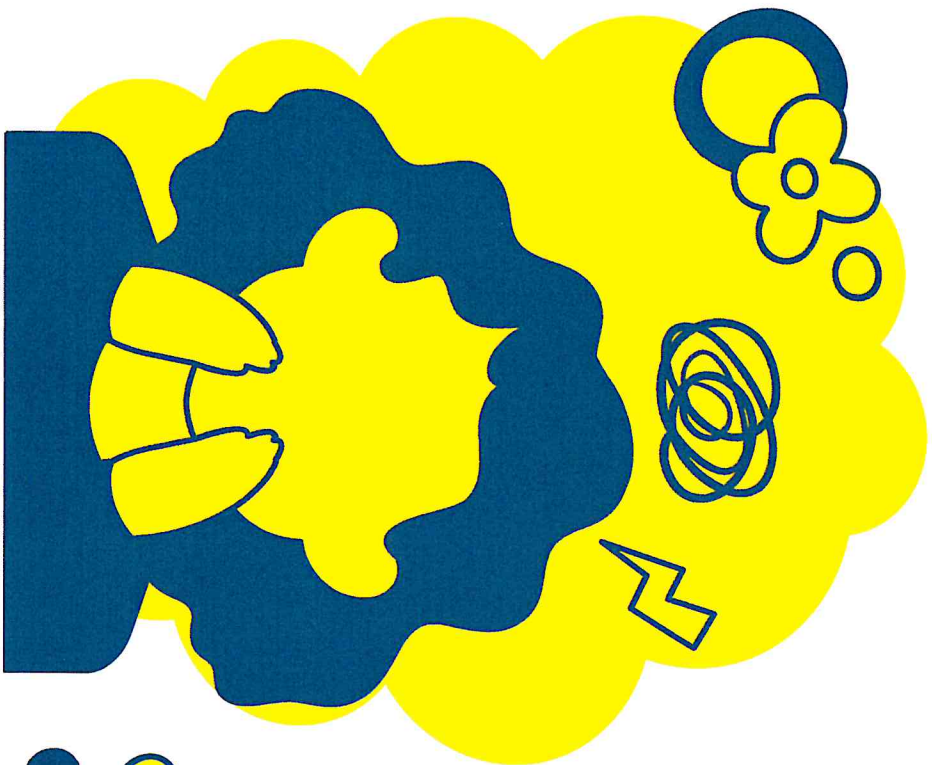
Get information from other sources
Have inaccurate or incomplete information
Potential for self harm or harm to others
Only abuse based information
Not natural to have sexual feelings
Touch is bad



Unwanted Outcomes

More likely to be abused
Won't understand consent
Can't identify when abuse happens
Unplanned pregnancy
Lonely and unfulfilled
Fixated on sexuality





When

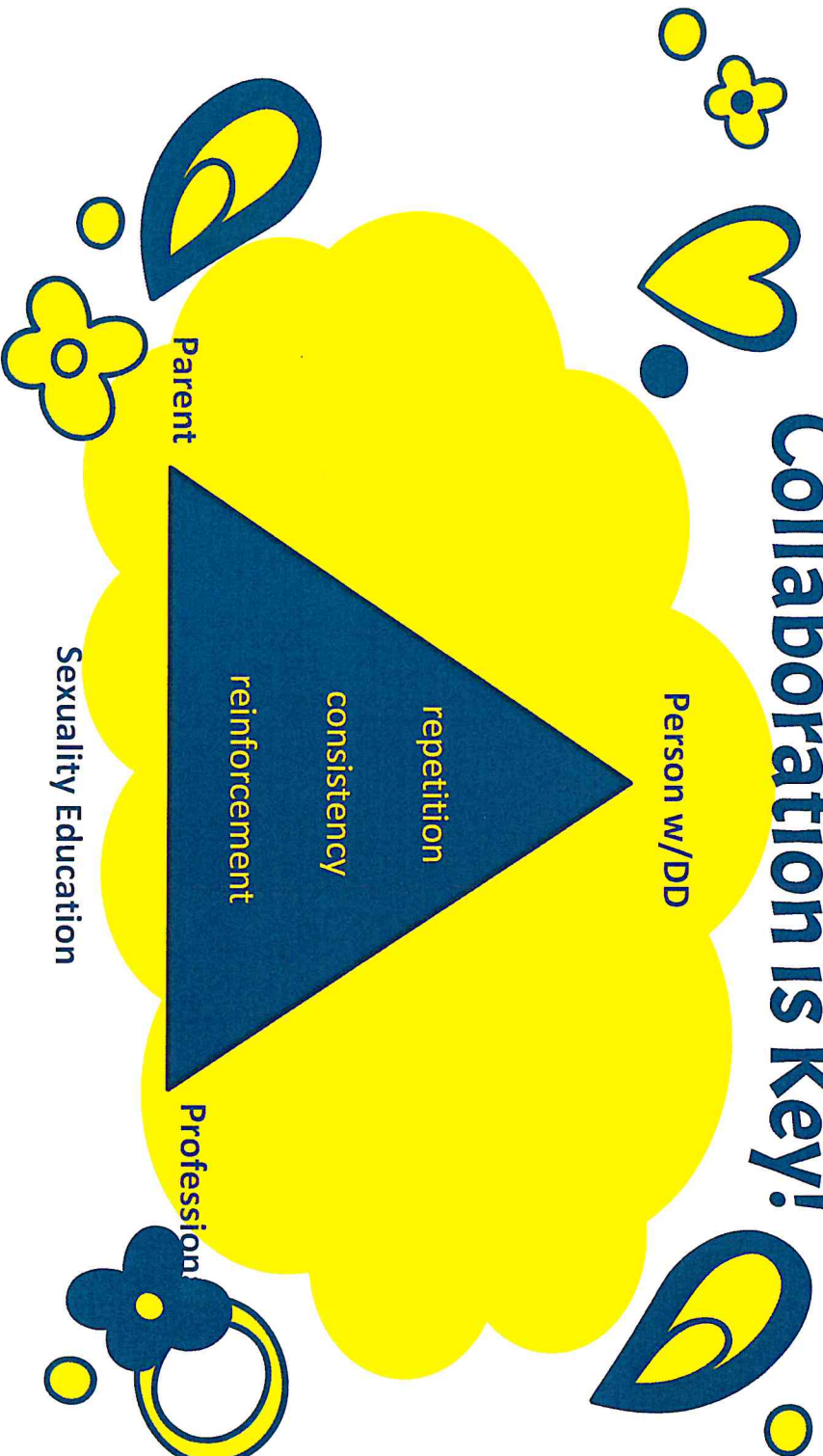
do I Start?

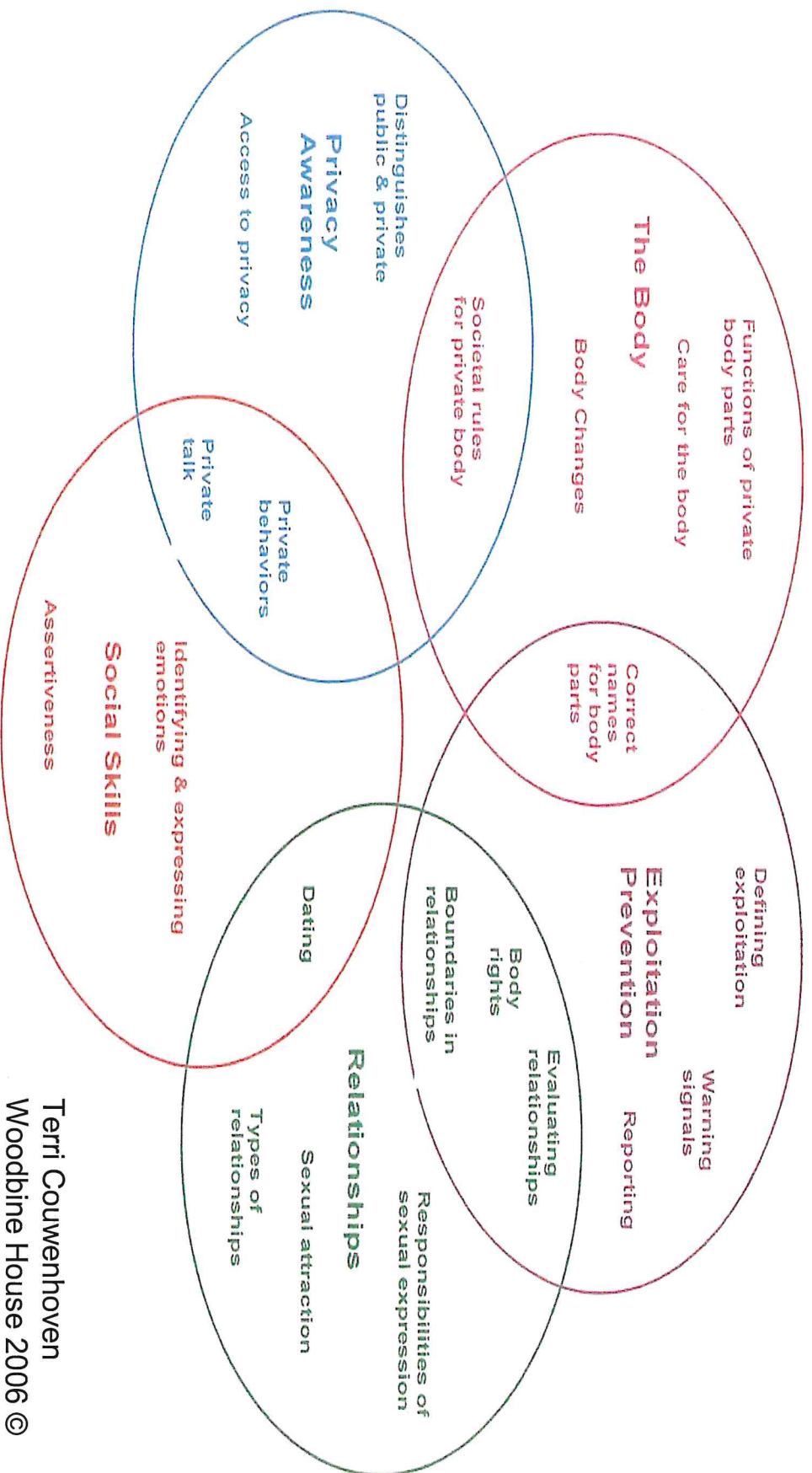
**It's NEVER too
early or too late.**

START

NOW!!

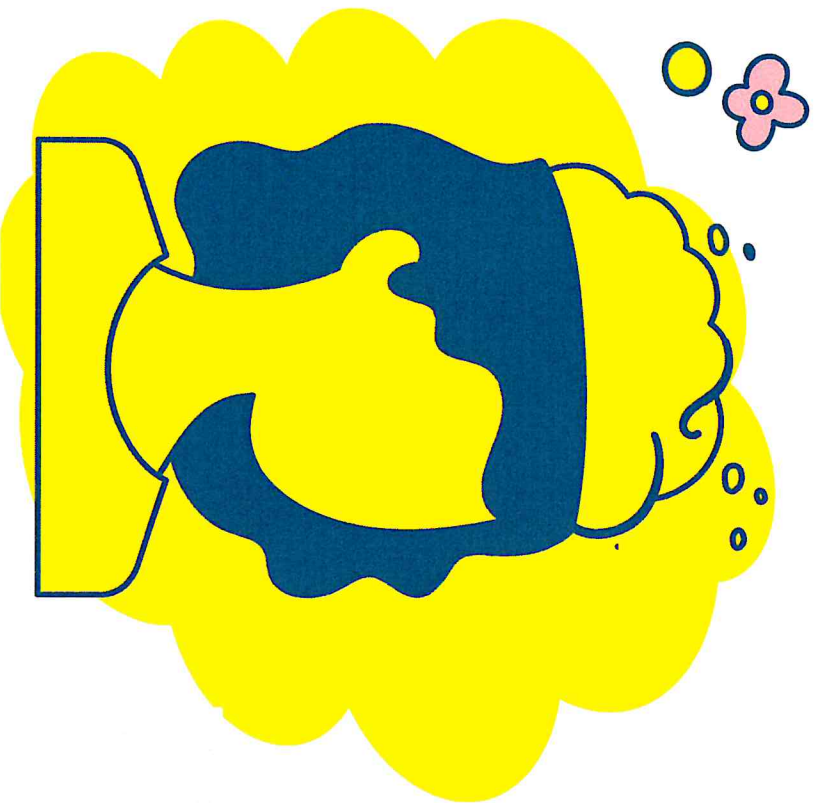
Collaboration is Key!





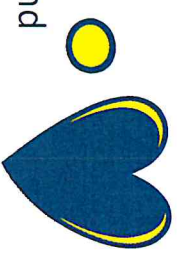
Terri Couwenhoven
 Woodbine House 2006 ©

What's Different?



Reliance on Others

Lack of autonomy and ability to make choices.



Lack of Privacy

Others involved in dressing, hygiene and medical needs. Constantly monitored by others

Loneliness

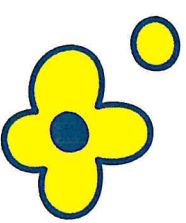
Lack of social opportunities or eligible dating/sex partners

Lack of Education

Exempted from school based Sex Ed programs, families don't want to discuss this topic



What's the Same?

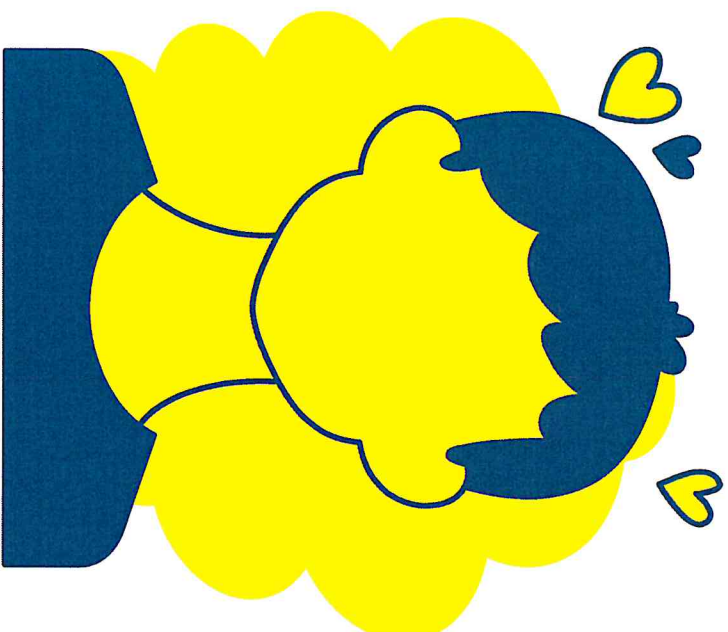


Puberty

Regardless of developmental age, the body is aging chronologically

Need for Information

Everyone deserves to be educated on their bodies



Desire to be Loved

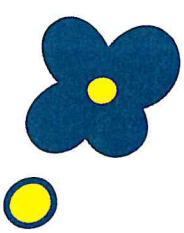
People with IDD are surrounded by others caring for them but are often lonely.

Confusion

Not sure who to ask or what to ask. Embarrassed they don't understand what is happening.



Important Discussions



Privacy and autonomy

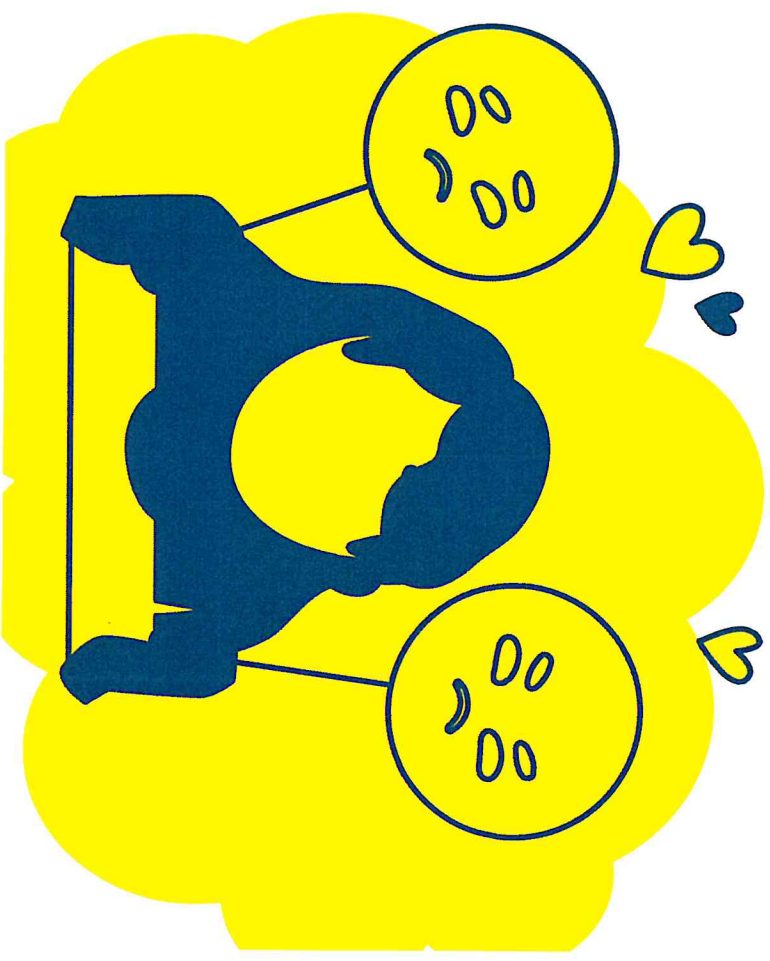
Very early on, who sees your body naked, who touches your body and when

Boundaries

When do I touch myself, when do I touch other people. Where and when can I explore my body

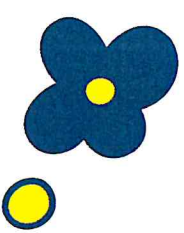
Consent

No one should touch you without your permission. You must have permission to touch others





Important Discussions



Body Parts

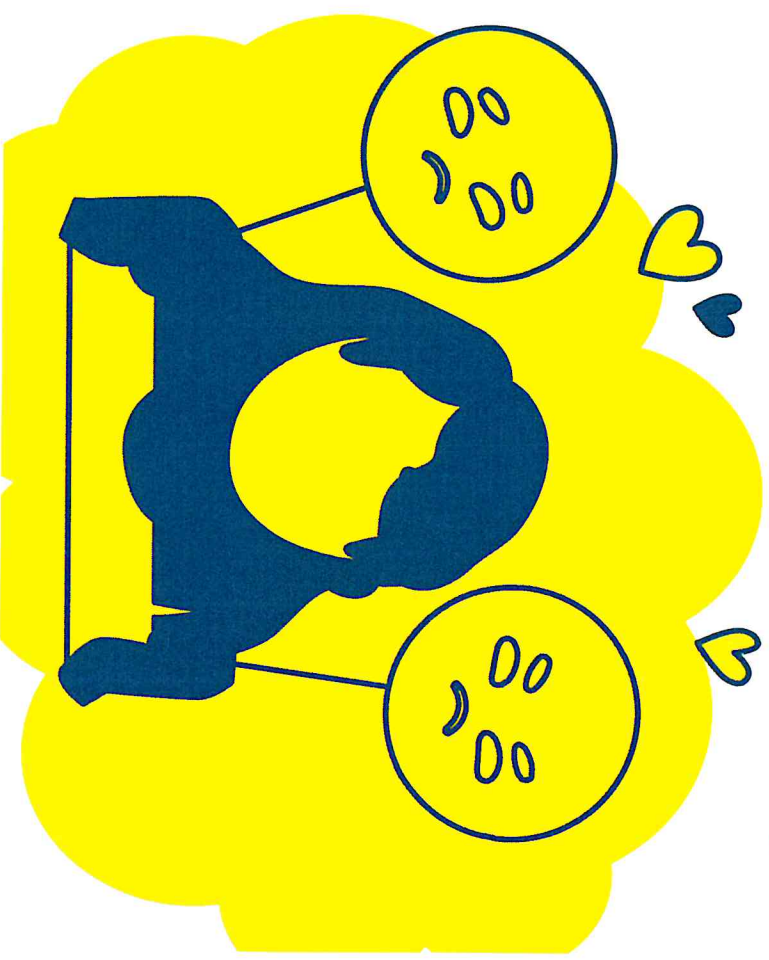
Use anatomically correct terms EVERY TIME!

Dating

When is it appropriate, who is appropriate to date, how do I find a partner?

Abuse Prevention

What abuse is and how to tell someone if you are being abused





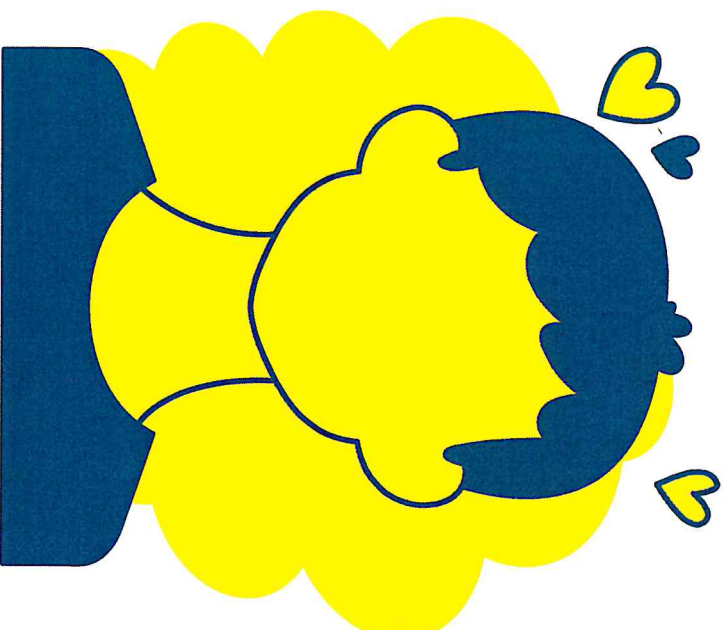
Public vs. Private

Be clear on where and when to explore your body or someone else's body.

Use Visuals

Body parts labeled
Steps to changing a maxi pad

How to help



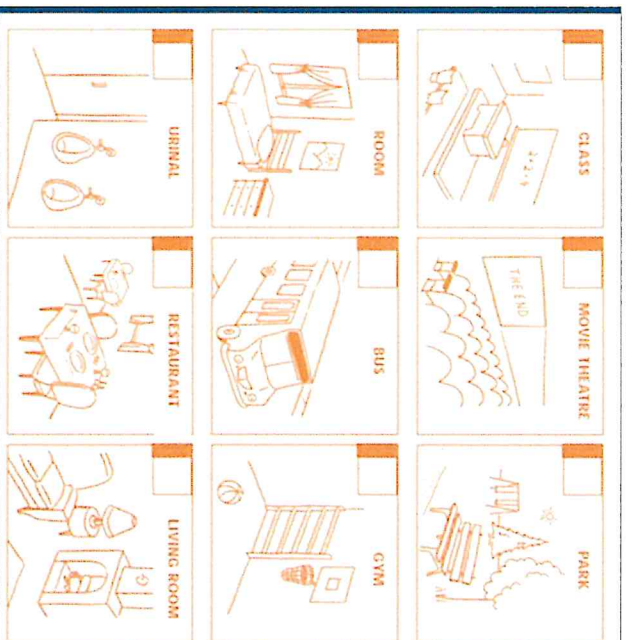
Social Stories

How/When do I kiss someone?
How/Where can I masturbate?

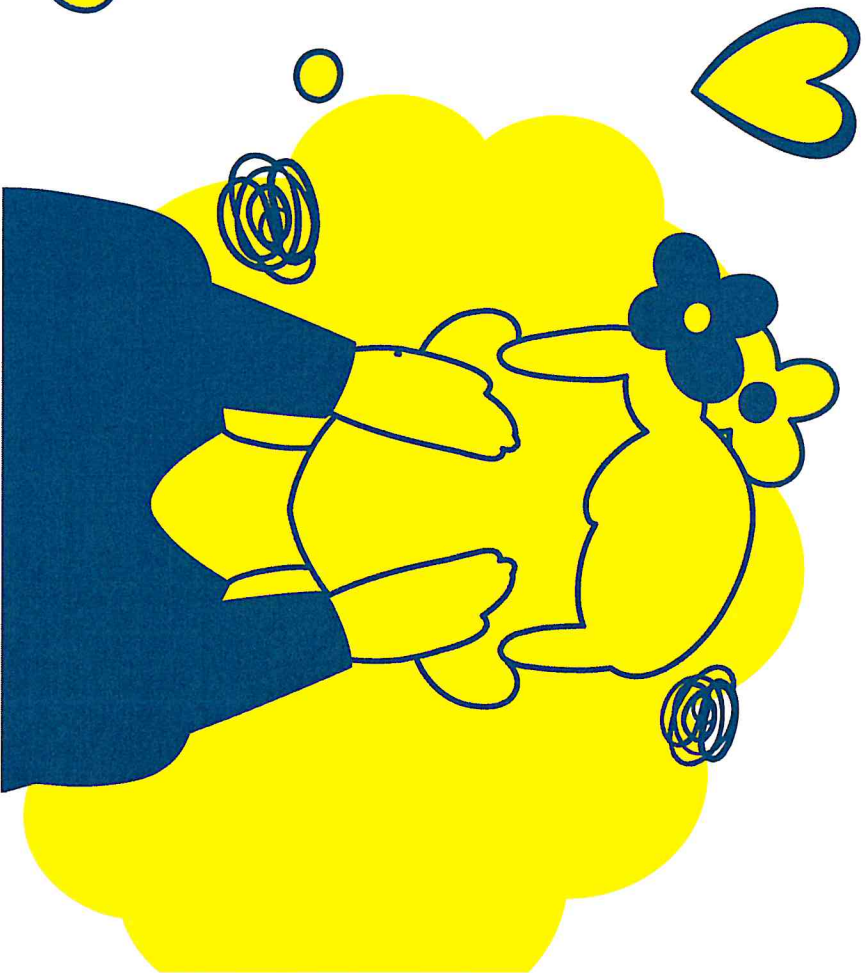
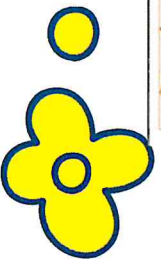
TV/Movies/Media

Highlight examples of love, sex and relationships that you are seeing in TV/Movies/Media

✿ Masturbation



Where and when is it okay to do this? How do I do this?





What is Consent:

When a person tells another person that it is okay to do something.

- If a person says they want to do something, then they consent.
- If a person says no or that they do not want something, they do not consent.

What Can I Do?



Teach how to read social cues	✓
Your body is your own	✓
Create vocabulary list	✓
Good touch vs Bad touch	✓
Create scripts and share	✓
Offer opportunities to talk	✓



Teaching Strategies



- **Visual**

Drawings, social stories, task analysis, photos, slides, diagrams, videos

- **Physical**

Identifying and touching body parts on people or dolls

- **Practice makes perfect**

Role play, dramatic play, real life experiences

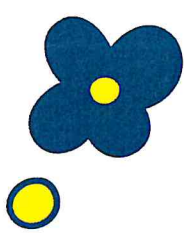
- **Repetition and reinforcement**

Use teachable moments
This is a process NOT one discussion
Look for others in same stage and connect





Menstrual Cycles



Can be Managed!

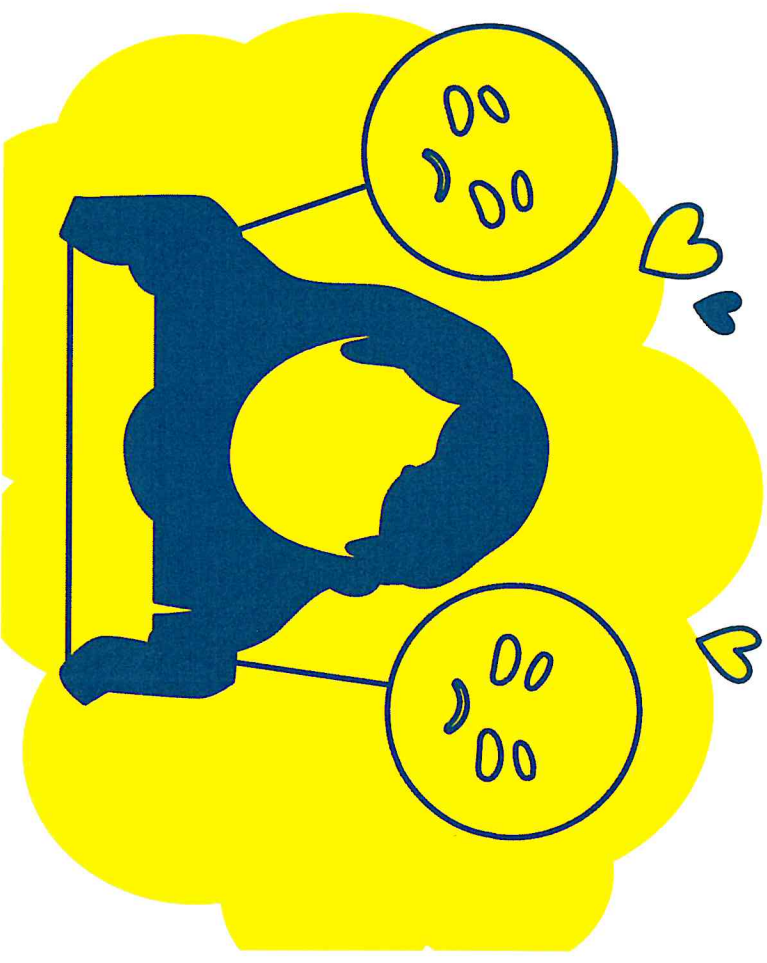
Teach early and prepare by trying on pads, tampons, period panties

Behavior Changes

Inability to express pain (cramps) or to handle hormonal changes each month can lead to behaviors or enhanced medical issues such as seizures increasing

Find Support

Ask other parents how they have managed menses





What if Things Aren't Working?

Use least restrictive approach to minimize risks and maximize self determination



Teaching

Team or family meeting to brainstorm new strategies and implement new teaching methods with more visuals

Hormonal Methods

Birth control pills
IUD
Depo Shot

Surgical Intervention

Ednometrial ablation
Hysterectomy



Sobering Statistics



**Adults with IDD are
SEVEN TIMES more
likely to be abused than
their typical peers**

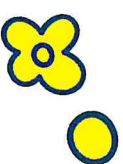
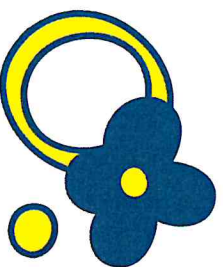
These crimes are under reported, under prosecuted and claims are difficult to substantiate due to working memory, verbal skills and ability to convey what happened consistently.

KNOWLEDGE IS POWER and can prevent the unthinkable from happening.



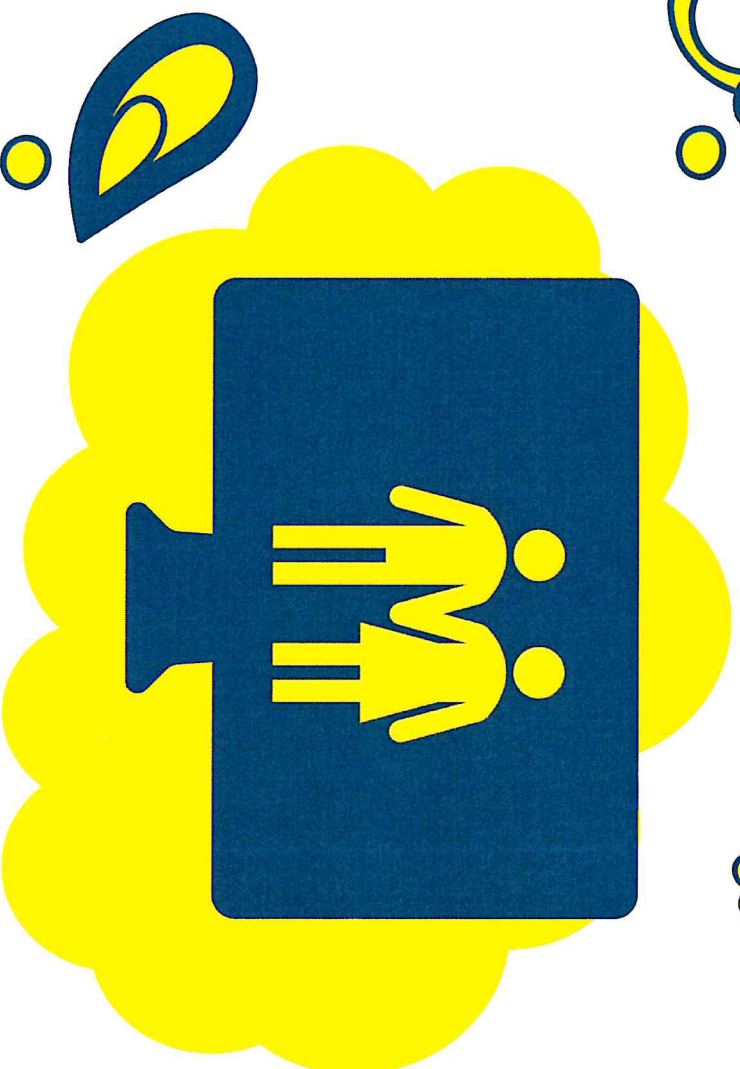
Relationships

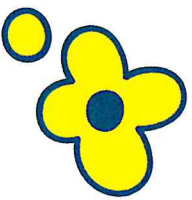
- Family
- Friends
- Co-workers
- Romantic
- Married



Key Topics

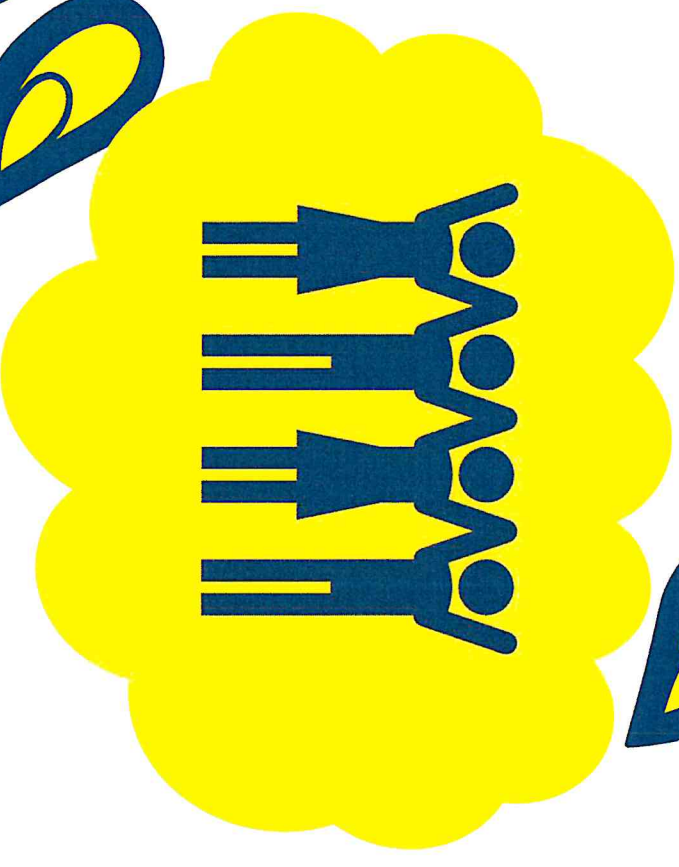
- Crushes
- Stalking
- Boundaries
- Consent
- Mutual





You can do this!

- Educate DON'T insulate
- Teach DON'T tell
- Consistency is key
- Find your tribe
- Process, not a one time discussion
- Two steps forward one step back
- Don't panic if you see regression
- What if everything

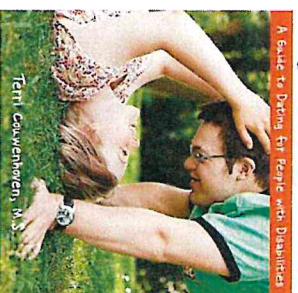
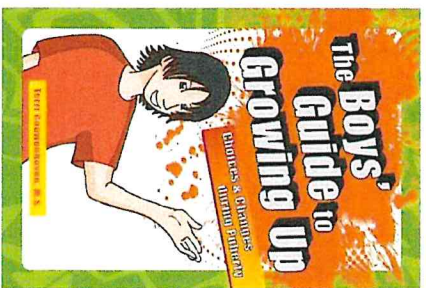




Terri Couwenhoven

Terri Couwenhoven MS, CSE is a well-known certified sex educator and author, specializing in the design and implementation of sexuality programs and resources for people with intellectual and/or developmental disabilities, their parents, and the professionals who support them.

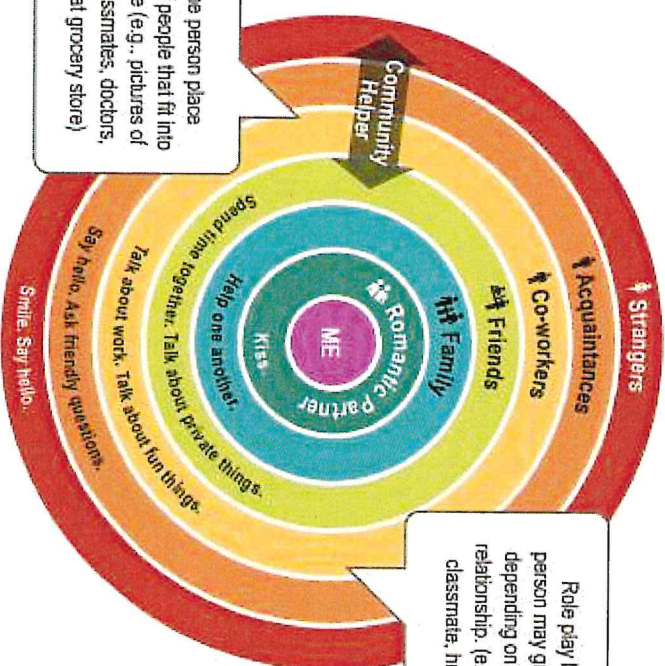
terricouwenhoven.com/work



Healthy Bodies

Parent Guides developed by national experts to help you walk your child through puberty and changes happening to their bodies.

vkc.vumc.org/healthybodies/



Have the person place pictures of people that fit into each circle (e.g., pictures of family, classmates, doctors, cashier at grocery store)

Role play how the person may greet people depending on the type of relationship. (e.g., high five classmate, hug parent)

Questions?

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