

NAVIGATING BOUNDARY CONFUSION IN PEOPLE WITH DOWN SYNDROME AND OTHER I/DD

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WHY BOUNDARY EDUCATION MATTERS FOR OUR CHILDREN..

- Expectations for community inclusion
- Vulnerability to exploitation
- Body autonomy (ownership and self determination)

“SEXUAL SCRIPTING” HAPPENS FOR ALL OF US

- Our culture defines and influences our behavior
- Learned “social rules/scripting” for sexual behaviors

John Gagnon (researcher)



BOUNDARY CONFUSION- INFANTILIZATION SCRIPTING

- Belief that people with I/DD are like perpetual children
- people commonly treated their “developmental” age vs. “chronological age”
- Way we/others think about people with I/DD impacts behavior

- What have you seen?



SEXUALITY EDUCATION: DEVELOPMENTAL VS. CHRONOLOGICAL

- **Developmental Age — “how”**
 - Use what you know:
 - Expressive & receptive language levels
 - Reading level
 - Communication methods (how do you check learning)
 - Range of sexuality topics
 - Scope and sequence
- **Chronological Age- “what”**
 - Societal rules and expectations
 - “teach to conservative norm”
 - David Hingsburger

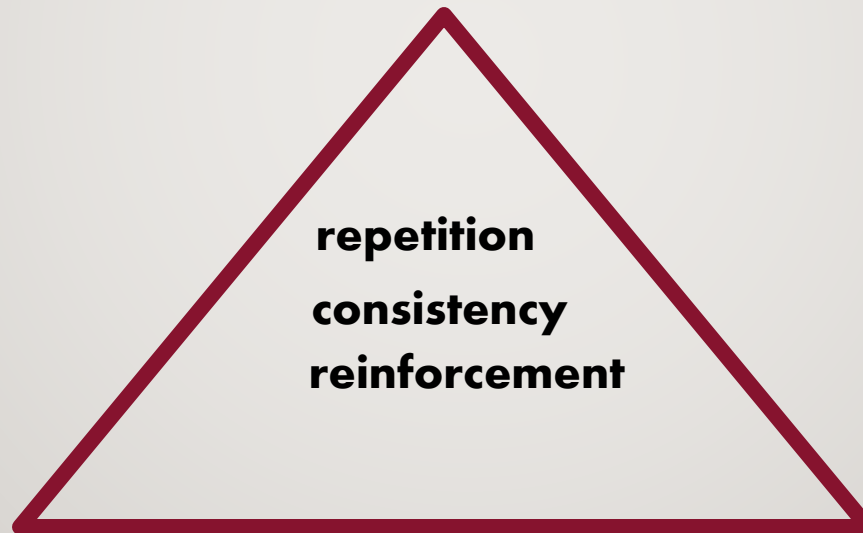


TEACHING BOUNDARIES - CHRONOLOGICAL AGE

- Use same-aged peers as a guide – Elementary, MS, HS, Community
- Use concrete life transitions linked to chronological age to introduce new or more age- appropriate interactions (nudging)
 - Puberty
 - Elementary → Middle → HS → Community
 - Birthday
 - Moving into community
 - Getting a job
- Share your goals with **EVERYONE!**

COLLABORATION IS CRITICAL

Person in I/DD- what is the goal?



Support Person

Parent

BOUNDARY CONFUSION- BODY DESENSITIZATION SCRIPTING

- Early and prolonged modeling ..
 - Therapies
 - Intimate care needs
 - Medical/health care
- Multiple caregivers over time with diverse perspectives about sexuality and boundaries
 - People with I/DD ARE sexual human beings
 - But the myths are still prevalent
- What have you seen?

CONSEQUENCES OF THIS SCRIPT....

- Diminished sense of modesty
- body ownership distortion
- Reduced awareness of personal space

BODY OWNERSHIP & AUTONOMY MESSAGES

- You are in charge of your body
- Most people will respect your body and boundaries.
- Some people do not get boundaries at all.
- As we get older (or once we are adults) we are expected to know about boundaries and let people know when they are crossing the line.

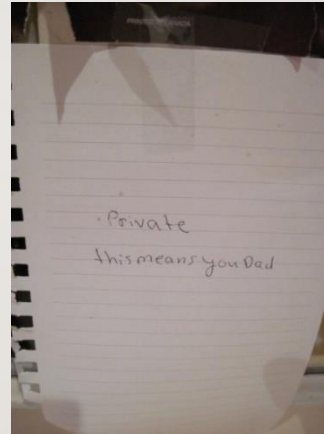


MODELING RESPECTFUL CARE (DAVID HINGSBURGER)

- Ask permission before moving into a person's private space, then wait for response (verbal or physical)
- describe what you are doing (context)
- encourage as much participation by individual as possible
- talk about the experience afterwards -read responses & moods following care

TEACHING ABOUT THE BODY & PRIVACY

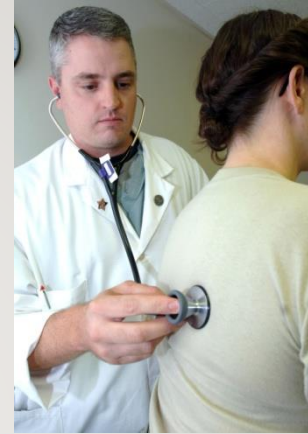
- Teach modesty
 - Is their body private?
 - Do they have a private place?
 - How can they express a need for privacy?
 - Do they know which behaviors are private?
- Teach names for private body parts then..
- boundaries and rules for private body parts



BOUNDARIES FOR PRIVATE PARTS



Touch involving **HYGIENE** (if need help)



Touch involving **HEALTH**



Consensual touch in **DATING RELATIONSHIPS**

BOUNDARY CONFUSION- RELATIONSHIPS

- Lack information about types of relationships
- Confusion regarding relationship roles & functions
- Exposure to multiple caregivers who all think differently about sexuality, relationships, and boundaries
- Dating & intimate relationships: Same feelings, same needs but less information!
 - Belief that crush = partner
 - What is mutuality/reciprocity? Why is it necessary?
 - How do you read signals of “interest” vs. “non-interest”
 - Are there people in your life who are off limits for dating?
 - What are sexual feelings and ways to handle them?


What have you seen?




TEACHING ABOUT RELATIONSHIPS & BOUNDARIES

PEOPLE IN MY LIFE


MY FAMILY – people related to me in some way




PAID HELPERS – people who are paid to help me (or others) in some way




FRIENDS – people I like to hang out with (face to face) in my spare time



ROMANTIC PARTNER – a person I am dating

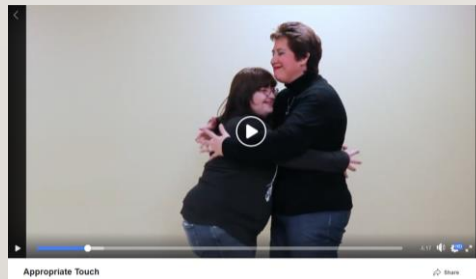
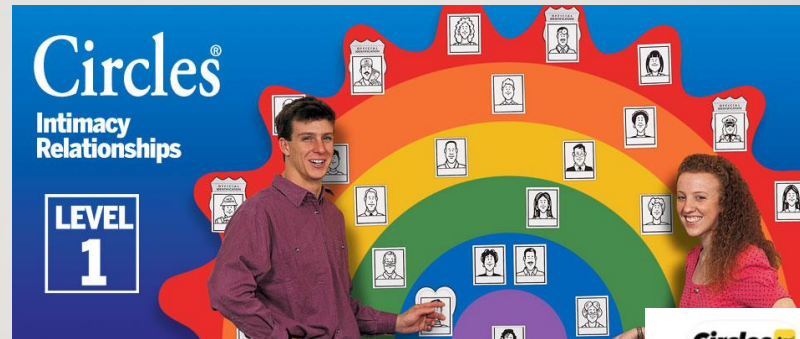


AQUAINTANCE – people I know, but don't hang out with



Circles®
Intimacy Relationships

LEVEL 1



Circles App Circles Social Skills Utility

Autism Social Learning Tool
James Stanfield Co., Inc.
Designed for iPad

4.5 stars (17+ Ratings)
\$39.99 - Offers In-App Purchases

iPad Screenshots



<https://www.facebook.com/adultdownsyndromecenter/videos/10155386416123576/>

TEACHING ABOUT BOUNDARIES IN RELATIONSHIPS: SOME GUIDING FACTORS

- Use same-aged peers as a guide
- Less we know someone, less we touch, share, trust
- Culture and community help us create guidelines but generalization can be a challenge. A set of concrete, conservative rules is often easiest
- Share goals with EVERYONE! Consistency is key!
- We all have touch needs! Ensure needs are being met..



TOUCH NOT OKAY IF..

- it is nonconsensual
- illegal
- harmful to self or others
- unwelcomed/unwanted...

Disability... or no disability

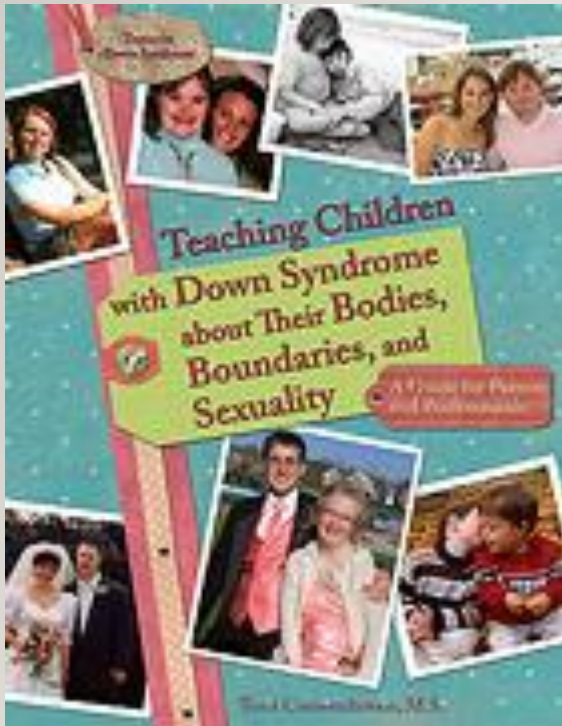


SUMMARY

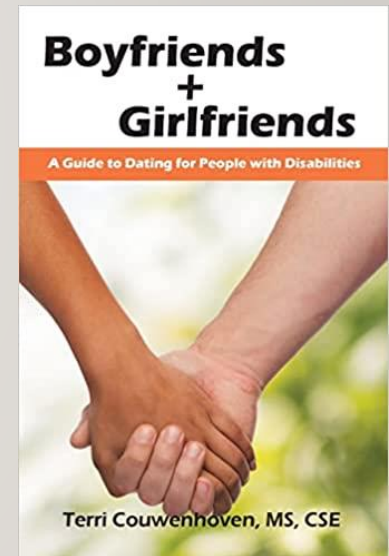
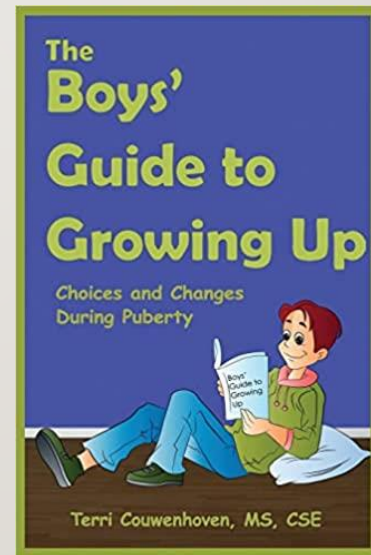
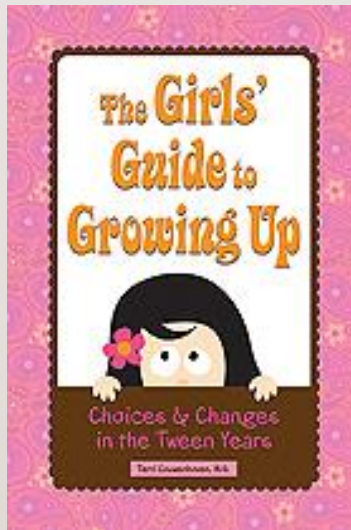
- Our attitudes about people with I/DD influence the ways we interact
- Unique scripts people with I/DD experience can create confusion related to boundary awareness.
- Education for caregivers AND people with I/DD is commonly a necessary component of boundary education.

COUWENHOVEN RESOURCES

FOR PARENTS & CAREGIVERS



FOR YOUR TWEENS, TEENS, & ADULTS



Puberty

Dating