

NAVIGATING BOUNDARY CONFUSION IN PEOPLE WITH I/DD

TERRI COUWENHOVEN MS, CSE
TCOUWEN@EXECPC.COM

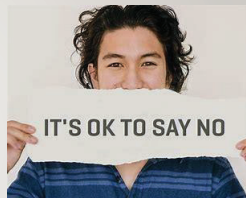


WHAT IS A BOUNDARY?



... a limit, edge, or line that deserves respect

WHY ARE BOUNDARIES IMPORTANT?



BOUNDARIES ARE A GOOD THING!

SAFETY



SOCIAL

APPROPRIATENESS



PROTECTING SELF



UNDERSTANDING BOUNDARIES ..WHY IS THIS IMPORTANT?

- Expectations for community inclusion
- Information supports social appropriateness and societal acceptance
- body autonomy (ownership rules)
- Vulnerability to exploitation
- As adults, legal issues

UNIQUE FACTORS CONTRIBUTING TO BOUNDARY CONFUSION

- **Infantilization**
- Modeled Desensitization
- Relationship Confusion
- Oversharing culture

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BOUNDARY CONFUSION- WHAT'S DIFFERENT?

- Belief that people with I/DD are like perpetual children
- Making assumptions about capacity based on physical appearance
- Treating people “developmental” age vs. “chronological age”

- What have you seen or experienced?

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SEXUALITY EDUCATION: DEVELOPMENTAL VS. CHRONOLOGICAL

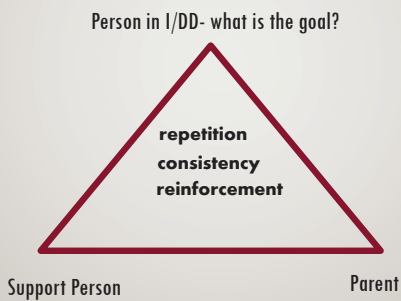
- | | |
|---|--|
| <ul style="list-style-type: none">• Developmental Age — “how”• Use what you know:<ul style="list-style-type: none">• Expressive & receptive language levels• Reading level• Communication methods (how do you check learning)• Focus on most immediate needs• Often narrower scope and sequence | <ul style="list-style-type: none">• Chronological Age- “what”• Societal rules and expectations• “teach to conservative norm”<ul style="list-style-type: none">• David Hingsburger |
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TEACHING BOUNDARIES - CHRONOLOGICAL AGE

- Use same-aged peers as a guide – Elementary, MS, HS, Adult 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



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BOUNDARY CONFUSION- WHAT'S DIFFERENT?

- 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 — Asexual or Hypersexual?
- What have you seen?

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CONSEQUENCES OF THIS SCRIPT . . .

- Body autonomy distortion
- Diminished sense of modesty
- Reduced awareness of personal space
- Inconsistency with modeling

RESPECTFUL CARE MODELING - MODELING (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?
 - Do they know which behaviors are private?
- Teach names for private body parts then..
- Teach boundaries and rules for private body parts

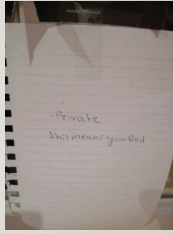


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TEACHING ABOUT THE BODY & PRIVACY

- Assessment
 - Is their body private?
 - Do they have a private place?
 - Do they know which behaviors are private?
- Boundaries for private body parts



BOUNDARIES FOR PRIVATE BODY PARTS



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



Touch involving **HEALTH**



Consensual touch in **DATING RELATIONSHIPS**

BODY RIGHTS MESSAGING

- 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.



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BOUNDARY CONFUSION – RELATIONSHIP CONFUSION

- Lack information about types of relationships
- Confusion regarding relationship roles & functions
- Exposure to large numbers of caregivers who all think differently about sexuality, relationships, and boundaries
- Dating & intimate relationships: Same feelings, same needs but less information!
 - Belief that crush = dating partner
 - Crushes on individuals providing paid support
 - What are sexual feelings and ways to handle them?

Have you observed relationship confusion? What have you seen?

RELATIONSHIPS & BOUNDARIES TEACHING

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

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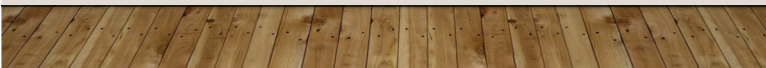
TEACHING ABOUT BOUNDARIES IN RELATIONSHIPS: SOME GUIDING FACTORS

- What's typical? Use same-aged peers as a guide
- Less we know someone, less we touch, share information, trust
- Culture and community influences rules but generalization can be a challenge. A set of concrete, conservative rules is often easiest
- Share goals with EVERYONE! Consistency is key!
- Touch is contextual! Model context for how and when you touch.
- We all have touch needs! Ensure needs are being met..



BOUNDARIES & RELATIONSHIPS: MESSAGING

- We decide our boundaries
- Other people decide theirs. It is common for others to have boundaries different than ours
- Other people decide what feels right for them
- If you're not sure...ask (consent)
- Stop means stop...for all of us!

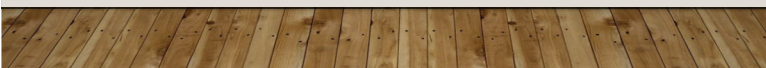


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TOUCH NOT OKAY IF..

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

Disability... or no disability



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SOCIAL MEDIA- INFORMATION SHARING

- Oversharing is common with EVERYONE!
- Be a good role model.
- Ask permission before sharing

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IDEAS- INFORMATION SHARING BOUNDARIES

What I Can Share on Social Media

Questions to ask yourself before you share...

- Why do I want to share this?
- Have I already shared a message/photo/video today?
- Will people want to see my message/photo/video?

When sharing a message...

- Use kind words.
- Make sure the information is public not private.
- Only share information that is not embarrassing for you and others.
- Check your spelling.

When sharing photos...

- Everyone should be wearing all their clothes and clothes should fit properly.
- Only public behaviors and not private behaviors should be included.
- Make sure you have permission to share the photo from each person in it.
- Consider whether you would be embarrassed if your parents, teachers, boss, etc. saw your photo.

When sharing videos...

- Everyone should be wearing all their clothes and clothes should fit properly.
- Only public behaviors and not private behaviors should be included.
- Make sure you have permission to share the video from each person in it.
- Consider whether you would be embarrassed if your parents, teachers, boss, etc. saw your video.
- Make sure the video is not too long.

Advocate Medical Group
ASL & Deaf Syndrome Center
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- Review public vs. private

- Social media is public

- Adult Down syndrome Center resource library (Social Skills)

DUAL ASPECTS OF TEACHING SEX. ED TO PEOPLE WITH I/DD

FACTS/ EXPLANATION	BOUNDARIES/ SOCIAL CONTEXT/RULES
Penis, vulva, butt, breasts are private body parts	<ul style="list-style-type: none"> - must be covered in public places, public rooms - if you need to look at or touch these body parts you need to be in private - touching rules for others
A <i>date</i> is a planned get-together between two people who might like to be a couple (or are already a couple).	<ul style="list-style-type: none"> - Who is an appropriate dating partner? - When is it okay to date?
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> .	<ul style="list-style-type: none"> - periods are private - if you need help you can talk to _____ at school and _____ at home

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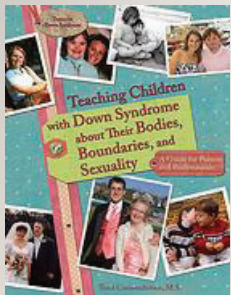
SUMMARY

- Boundaries are a good thing!
- Our attitudes about people with I/DD influence the ways we interact
- Unique circumstances 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.

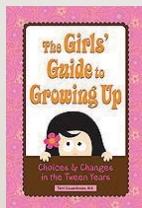
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COUWENHOVEN RESOURCES

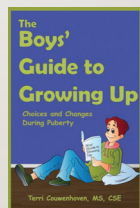
FOR PARENTS & PROFESSIONAL



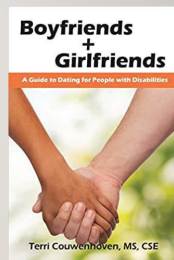
FOR PEOPLE WITH I/DD



Puberty



Dating



Dating