

LET'S TALK: SEXUAL HEALTH EDUCATION

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1

Objectives



- Examine barriers to talking about sexual health with individuals with IDD
- Recognize the importance and benefits of discussing sexual health with individuals with IDD
- Gain comfort and confidence in addressing SHE topics with individuals with IDD

2

BARRIERS TO SEXUAL HEALTH EDUCATION



3

Sexual Health Education (SHE)



- When we hear about sexuality education, we often automatically think about sexual activity, and, understandably, this often causes concern
- Human sexuality education is more than teaching about sexual activity
- It should be an ongoing process starting early and encompassing basic body awareness, health information, communication skills, decision-making, and social skills

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Challenging Subject Matter

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5

5

Think about your own Sexuality Education

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- How did your family express affection?
- What gender roles were modeled?
- What topics were discussed as you developed & what topics weren't?
- Where did you get information about puberty, dating, and sex?
- Did anyone teach you about sexual pleasure?
- Were the messages you received predominantly positive/negative/neutral?
- How does this impact your ability to talk about sexuality?
- What messages do people with IDD get?
- How similar or different are they to the messages you got?

6

6

Barriers

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When you think about talking about sexuality and sexual health with individuals with Down syndrome, what barriers do you face?

7

7

Research: SHE for People with IDD

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Bernard-Brak, et al. (2014) conducted an analysis of data to define predictors of whether students with IDD accessed SHE in public schools across the US

- Of students receiving special education services, the following percentages accessed SHE
 - 47.5% of students with no ID
 - 44.1% of students with mild ID
 - 16.18% of students with moderate to profound ID
- EC teachers' reported perceptions of whether students receiving special education would benefit from SHE
 - 60% believe students with no ID would benefit from SHE
 - 68% believe students with mild ID would benefit from SHE
 - 25% believed students with moderate to severe ID would benefit from SHE
- The single significant demographic predictor of EC students accessing SHE was higher expressive communication skills

8

8

Research: SHE for People with IDD (cont.)



- The Council on Quality and Leadership (QCL; Friedman & Owen, 2017) researched sexual health related services provided by Medicaid Home and Community-Based Services (HCBS) waivers for people with IDD
 - Of 111 waivers from 46 states and DC, less than 12% offered any sexuality-related service
 - Of the those that did, the majority were “reactive” or in response to sexually problematic behaviors, while few provided proactive services

9

Research: SHE for People with IDD (cont.)



- 2015 literature review (Sinclair, et al.) indicated 3 themes among numerous barriers to SHE for individuals with IDD:
 - perceptions of others about individuals with IDD and their sexuality
 - perceptions of individuals with IDD about their own sexuality
 - sexuality knowledge of individuals with IDD
- Several studies have shown that SHE can help individuals with IDD increase knowledge related to sexual health and abuse (Murphy, 2003; McDermott et al., 1999; McCann, et al., 2019; Schmidt, et al., 2019)
 - One study indicated positive outcomes for SHE provided in 1:1 setting and adapted to individual learning style and ability as well as retention of new knowledge over time (Dukes & McGuire, 2009)
- Sinclair, et al. (2015) also argued that a person with IDD’s quality of life, access to SHE, and informed decision-making ability about sex, requires change across national, state, residential, school/classroom, and individual levels

10

Myths



- **Myth: you should focus on the cognitive age of the child**
- **Myth: if we talk about it, they will do it**
- **Myth: sexuality education is teaching them to have sex**
- **Myth: sexuality education teaches someone else’s values**

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False Messages about People with Developmental Disabilities




- Are not sexual beings
- Should not have sex
- Are innocent and childlike and need protection from sexuality
- Are not responsible
- Cannot solve problems
- Are unable to make good decisions about sexuality
- Always make mistakes
- Would not make good parents so should not have children
- Are different than their non-disabled siblings

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12


Common Misbeliefs	Policy and Practice	Outcomes
Childlike Innocence	Overemphasize protection and undervalue their children's autonomous right to express sexuality and experience intimate relationships	Shielding individuals with IDD from information about sexuality disempowers them and exacerbates their risks for sexual violence
Oversexed/Sexually Aggressive	Oppression based on fear that information will exacerbate or result in inappropriate sexual behaviors. Exclusion from school-based SRE or limited SRE instruction focused abuse protection and risk avoidance	Abuse protection and risk avoidance dominate and overshadow information that affirms positive aspects of sexuality and encourages healthy psychosexual development
Asexual – No Interest	Presumption that sexuality education is irrelevant, Deprioritized SRE for this population, problem-based model for sexuality education, sexual health topics are avoided or seen as irrelevant	Limited access to SRE or a limited curriculum focused on abuse protection and harm reduction. Maladaptive understanding of human sexuality and relationship intimacy.

13



IMPORTANCE OF SEXUAL HEALTH EDUCATION

14




IDD Community is a vulnerable population...

- **People with IDD: 7x** more likely to be sexually assaulted than general population
- Nearly **90%** of women with I/DD experience sexual assault during their lifetime
- **49%** of individuals with I/DD will experience **more than 10** incidents of sexual assault

Board Resource Center & The Arc's National Center on Criminal Justice and Disability 15

15



Children with IDD are vulnerable, too

Although there is variation in results of studies analyzing the extent of sexual abuse in children with disabilities, research suggests

- Estimated 14-32% of children with ID have experienced sexual abuse (mean prevalence of 15%)
- Children with ID were 4 to 8 times more likely to experience sexual abuse than those without ID
- Of all children with disabilities, those with ID are among the highest risk groups for sexual abuse

(Wissink, 2015)

16

Complex Issue:
NPR's *Abused and Betrayed*

<https://www.npr.org/series/575502633/abused-and-betrayed>

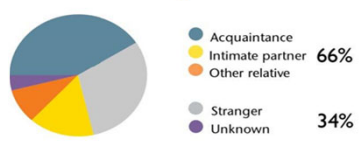
- Limited self-advocacy skills and sexuality education
- Lack training: families, educators, services providers, SARTs (law enforcement, SANEs, rape crisis centers)
- Limited public awareness
- Need for systemic change

17

Complex Issue (cont.)

- Among women, only **14%** of SA committed by strangers
- The **vast majority are known and trusted** by the individual

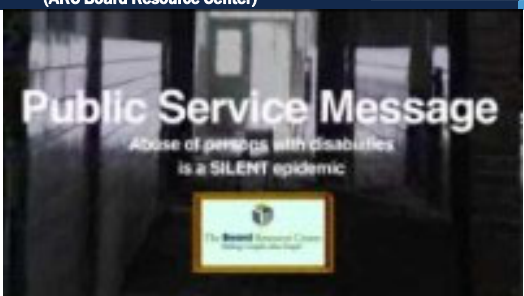
Relationship to Offender



Relationship	Percentage
Acquaintance	66%
Intimate partner	
Other relative	
Stranger	34%
Unknown	

18

Abuse of People with Disabilities:
A Silent Epidemic
 (ARC Board Resource Center)

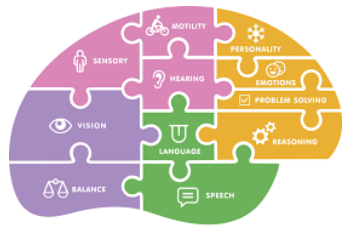


<https://www.youtube.com/watch?v=vhLsATw00o4>

19

Why are people with I/DD more vulnerable?

- Social Cognitive Deficits
 - Reading subtle cues
- Executive Functioning
 - Planning and organization
 - Impulsivity
- Central Coherence
 - Theory of Mind
- Cognitive Impairments
- Communication Impairments
- Compliance
 - Need to rely on others



<https://images.app.goo.gl/DGA5ikSMQSLaEKIM9>

20

Restrictions, Power, Companionship, and Intimacy: A metasynthesis of People with Intellectual Disability Speaking About Sex and Relationships
Rhonda S. Black and Rebecca R. Kammes

A desire for intimacy
BUT
Restrictive programs/policies/family rules form obstructions

A desire for friendships/peers
BUT
Others in control of their social lives

A desire for a sexual identity and experiences
BUT
Family/staff/societal expectations create barriers

Punished for intimate experiences
Loneliness
Sex as secretive
Abusive experiences
Focus on abuse prevention and not desire/positive experiences

Figure 1. Competing themes of control and desire. <https://www.evaluationtraining.com/listening-to-self-advocates-voices>

21

Even More Vulnerable

Greater vulnerability associated with certain diagnoses:

- ID
- ADHD
- ASD

<https://images.app.goo.gl/iHdeMf9b9sNPzuQB7>

22

How do we reduce sexual violence among individuals with I/DD?


Individuals	Caregivers	Community
<ul style="list-style-type: none"> • Self-Advocacy • Comprehensive Sex Education • Sexual Health • Social Skills Training 	<ul style="list-style-type: none"> • Clarify values • Education regarding risks • Encourage Communication • Modeling appropriate behaviors 	<ul style="list-style-type: none"> • Sexual diversity education • Sensitivity training • Establishing community partnerships • Training for sex educators

We'll focus mostly on sexual health education!

23

- Importance of SHE**
- Be prepared for changes that occur in our bodies, our emotions, our relationships
 - Respect the boundaries of others and expect that others will respect our own boundaries by asking for consent
 - Develop the tools necessary to communicate effectively and assertively and make informed decisions about sexual health
 - Recognize signs of Healthy and Unhealthy relationships
 - Be better prepared to live and participate as independently and safely as possible in the community

24



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SEXUAL HEALTH AND RELATIONSHIP EDUCATION

25

25

Parents/Caregivers are the primary
sexuality educators of their children



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26

26

Parental/Caregiver Uncertainty



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- May be uncomfortable talking about reproductive body parts and functions
- The topic of sex may not have been discussed when they were growing up
- May fear that talking about sexuality and reproduction will encourage children to experiment
- May be unsure about how to adapt the information to fit child's cognitive/developmental level




27

27

Common Questions
Parents/Caregivers Have



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- How do I teach my daughter about having her period?
- Will my child develop sexually at the same rate as his/her friends?
- How do I explain to my child that masturbation is a private activity?
- How do I help my child navigate the world of dating?
- How do I keep my child safe?

28

28

What Parents/Caregivers Should Know

As parents/caregivers, you are already teaching your children many things about sexuality and have been since the day they were born. They learn from:

- the way they are touched by others
- the way their bodies feel to them
- what your family believes is okay and not okay to do
- the words that family members use (and don't use) to refer to parts of the body
- watching the relationships around them

29

29

Prevention through Education

Sexuality Information and Education Council of the United States (SIECUS)

<https://siecus.org>

Comprehensive sexuality education

- Health Promotion
- Risk Reduction
- Harm Prevention

sex ed.

sex ed for social change.

<https://images.app.goo.gl/c19R0b5tN1A5EK7>

<https://images.app.goo.gl/cwVIEN5CCPmrx8d9>

30

SIECUS: National Sexuality Education Standards (NSES)

- ❖ Curriculum should incorporate information, skills, and exploration of values
- ❖ NSES Focus Areas
 - Consent and Healthy Relationships (CHR)
 - Anatomy and Physiology (AP)
 - Puberty and Adolescent Sexual Development (PD)
 - Identity (ID)
 - Gender Identity and Expression (GI)
 - Sexual Orientation and Identity (SI)
 - Sexual Health (SH)
 - Interpersonal Violence (IV)

National Sexuality Education Standards

<https://siecus.org>

31

31

Sexuality and Relationship Education for People with IDD & Caregivers/Support Person

32

32

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- Bodily Autonomy and Consent ←
- Human Development/Life Cycle
- Sexual Anatomy & Physiology
- Gender Identity and Expression
- Reproduction
- Puberty
- Types/Stages of Relationships ←
- Laws, Safety, & Boundaries ←
- Sex, Sexuality, and Healthy Behaviors ←
- Flirting, Dating, and Intimate Relationships ←
- Unhealthy vs. Healthy Relationships ←
- Internet, Technology, and Social Media ←

P RIVATES ARE PRIVATE
A LWAYS REMEMBER YOUR BODY BELONGS TO YOU
N O MEANS NO
T ALK ABOUT SECRETS THAT UPSET YOU
S PEAK UP, SOMEONE CAN HELP

<https://images.app.goo.gl/3V1m1v10GzG2m2>

33

33

The Role of CAREGIVERS in SRE

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- Start conversations
- Better understand family member's perspective
- Give correct information about sex and teach them to use correct language for their own body parts
- Answer questions honestly
- **Share family beliefs, concerns and values**
- Talk with child's teachers as well

Let's Talk!

<https://images.app.goo.gl/3V1m1v10GzG2m2>

34

34

Open Communication

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To open and maintain the lines of communication between you and your child(ren):

- Respect their views and validate their feelings
- Demonstrate responsible, health-conscious decisions
- Avoid acting as if you already know everything
- Stay involved in their lives to help your teen feel connected to you
- Speak to them as a mature person
- Recognize you can't control all of your teen's actions

35

35

Family Values

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PLURAL NOUN: the moral and ethical principles traditionally upheld and transmitted within a family, as honesty, loyalty, industry, and faith

- It's important for parents to make sure their values are also heard and assist their children in thinking critically about what they learn from the media, friends, etc.
- Research indicates that parents who communicate clear values to their children about abstinence and/or contraceptive use are more likely to have children who delay the onset of sexual intercourse and/or use contraception effectively
- Teachable moments are all around us and allow us the opportunity to share information and values with our children

36

36

Common Values

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Common values that we can all agree upon are **OKAY** to express:

- ❖ It is important to **respect** others by treating them well and listening to them
- ❖ It is important to get **consent** from a sweetheart for being sexual
- ❖ It is important to be **responsible** in a romantic relationship
- ❖ Relationships should be **equal and positive** without violence or abuse
- ❖ Sex should be **safe and pleasurable** for all

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37

Terri Cowenhoven: The Four P's

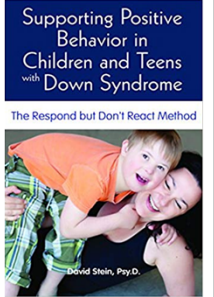
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The Four P's-

- ❖ Permission
- ❖ Privacy
- ❖ Pleasure
- ❖ Protection

If you follow The Four P's while having a sexual relationship, you will be **LEGAL** and **SAFE**

Supporting Positive Behavior in Children and Teens with Down Syndrome
The Respond but Don't React Method




Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality. Terri Couwenhoven. Woodbine House. 2007

38

Where to Start?

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With the basics:

- Use correct terminology
- Provide accurate information
- Encourage questions

39

39

Teaching Strategies

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Universal Design Learning (UDL)	Instructional scaffolding	Be clear, concrete, and matter of fact
Small groups/ Peer pairing	Multi-modal learning	Slower pace
Repetition, Repetition, Repetition!	Teachable moments	Check for comprehension

40

40

Three UDL Principles

- Multiple, flexible methods of **Presentation or Representation**
 - Provide various ways to acquire information and knowledge
- Multiple, flexible options for **Participation and Engagement**
 - Motivate learning by gaining interests and creating challenge
- Multiple, flexible means of **Expression**
 - Provide alternative ways to demonstrate acquired knowledge

<https://www.dimpd.com/universal-design-for-learning/>

41

Multi-Modal Learning

- Modeling concepts of consent and bodily autonomy
- Relating to personal experiences
- Visual aids and supports
- Graphic organizers
- Hands-on activities
- Brainstorming/webbing
- Role plays
- Social Behavior Mapping
- Video Modeling

<https://images.app.goo.gl/SL4Jh5Row71TQSM8>

42

Beginning Early!

My Body Safety Rules

My body is my body and it belongs to me!

I have a Safety Network

Early Warning Signs

Secrets

Private Parts

NO GO TELL

Unsafe Touches

Safe Respect Boundaries Empowered Comfortable

<https://www.unc.edu/daas/online/55602/>

43

"May I?" Movement

Date Safe Project (now called Center for Respect)



- Asking First for Consent
- Making Smarter Choices with Partners
- Supporting Survivors of Sexual Violence
- Intervening when Danger is Present at Parties and Group Settings with Alcohol

<https://images.app.goo.gl/07HRkS8mVxgP0p9>

44

Consent

- **Consent** means I ask your permission, and you say "yes"
 - I ask you if I can touch you, and you say "yes"
 - Example:
 - Me: "May I hold your hand?"
 - You: "Yes"
- **Consent** means you ask my permission, I say "yes"
 - You ask me if you can touch me, and I say "yes"
 - Example:
 - You: "May I give you a hug"
 - Me: "Yes"
- **Consent** means you and I both say "yes"
 - We both say "yes"
- Sometimes when we ask for **consent**, people say "no"
 - If people say "no," they do not give consent and do not want you to touch them
 - If someone says no, you should not touch them

45

CONSENT



Consent starts with asking. Ask the person for permission.



Listen to the person's answer.



They might say yes or no. Respect their answer.



Some people give consent using words.



Some people give consent using body language.



Some people use assistive technology to communicate consent.

46

CONSENSUAL TOUCH

Consent is when I give permission to touch my body.	People should ask permission before they touch my body.	I give consent when I say "yes."
		
If someone wants to hold hands or kiss, I can say "yes" if I want to.	If I do not want someone to touch me, I can say "no." I do not give consent for them to touch me.	If I say "yes" but change my mind, I can say "no." That person should stop touching me.
		

47

CONSENT

for
KIDS

<https://youtu.be/h3nhM9UJjc?t=3>

48

Verbal Signals of Consent and Nonconsent


What can consent sound like?	What can nonconsent sound like?
Yes	No
I'm sure	I'm not sure
I know	I don't know
Don't stop	Stop
Whoohoo! Yippeee! Hot damn! Zip-a-Dee-Doo-Dah!	[Silence]
Dahl!	No more
I want to ...	I want to, but ...
I'm not worried	I feel worried about ...
I want you/it/that	I don't want you/it/that
Can you please do [whatever]	Can you please not do [whatever]
I still want to ...	I thought I wanted to, but ...
That feels good	That hurts
Mmmmmmm	[Silence]
Yes	Maybe
I love you/this	I love you/this, but ...
I want to do this right now	I want to do this, but not right now
I feel good about this	I don't know how I feel about this
I want to keep doing this	I don't want to do this anymore
[insert praise to your deity of choice here]	[insert pleas for help to your deity of choice here]
This feels right	This feels wrong
Yes	[Silence]

49

Nonverbal Consent

Possible nonverbal signs of consent	Possible nonverbal signs of NONconsent
Direct eye contact	Avoiding eye contact
Initiating sexual activity	Not initiating any sexual activity
Pulling someone closer	Pushing someone away
Actively touching someone	Avoiding touch
Nodding yes	Shaking head no
Comfort with nudity	Discomfort with nudity
Laughter and/or smiling (upturned mouth)	Crying and/or looking sad or fearful (clunched or downturned mouth)
"Open" body language, like relaxed, loose and open arms and legs, relaxed facial expressions, turning towards someone	"Closed" body language, like tense, stiff or closed arms and legs, tight or tense facial expressions, turning away from someone
Sounds of enjoyment, like a satisfied hum or enthusiastic moan	Silence or sounds of fear or sadness, like whimpering or a trembling voice
An active body	"Just lying there"

50



Signs You Should Stop


- You or a partner are too intoxicated to gauge or give consent.
- Your partner is asleep or passed out.
- You hope your partner will say nothing and go with the flow.
- You intend to have sex by any means necessary.


Signs You Should Pause and Talk

- You are not sure what the other person wants.
- You feel like you are getting mixed signals.
- You have not talked about what you want to do.
- You assume that you will do the same thing as before.
- Your partner stops or is not responsive.

Keep Communicating


- Partners come to a mutual decision about how far they want to go.
- Partners clearly express their comfort with the situation.
- You feel comfortable and safe stopping at any time.
- Partners are excited!
- You assume that you will do the same thing as before.
- Your partner stops or is not responsive.





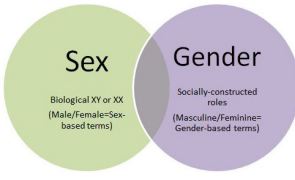
51

51



Difference Between Sex and Gender

- Sex = biological status as male or female. It includes physical attributes such as sex chromosomes, gonads, sex hormones, internal reproductive organs, external genitalia**
 - These are the same across cultures
- Gender = how one acts, interacts, and feel about themselves and their sex**
 - Varies across cultures



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HOW THE BODY CHANGES DURING PUBERTY

Male Changes	Female Changes
Hair: on face, on chest, in pubic area, under arms, on legs.	Hair: in pubic area, under arms, on legs.
Growth: sexual parts and the whole body grows.	Growth: sexual parts and the whole body grows.
Sperm develops: boys start to make sperm in their testicles.	Ovulation: eggs begin to pop out of the ovaries.
Ejaculation: semen comes out of the penis.	Menstruation: bleeding out of the vagina once a month.
Erections: The penis gets hard more often.	Vaginal Lubrication: the vagina gets lubricated or wet more often.
Sexual feelings are feelings of being attracted to or wanting to do sexual things.	Sexual feelings are feelings of being attracted to or wanting to do sexual things.

B.O. (Body Odor)

begins to get hair on face & legs
hair grows underarms
skin & hair get more oily
voice gets deeper
penis grows
testes begin to grow
sperm production begins
gets sexual feelings
has wet dreams (sexual arousal/orgasms during sleep)

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Typical Development of the Male Body

- ▶ Deeper Voice
- ▶ Body Odor
- ▶ Bigger Muscles
- ▶ Larger Genitals (Penis and Testicles)
- ▶ Increased Hormones
- ▶ Nocturnal Emissions (Wet Dreams)

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Typical Development of the Female Body

- ▶ Body Odor
- ▶ Breasts Develop
- ▶ Larger Pelvis (Hips)
- ▶ Body Hair Appears
- ▶ Increased Hormones
- ▶ Menstruation (Getting a Period)

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Hygiene Responsibility Chart

Body Changes	My responsibilities	Things I Will Need
Sweat/body odor		
Oilier skin & hair		
Zits/acne		
More body hair		
Breasts		
Menstruation		
Height/weight increases		
Thinking/curious about sex		
Emotions are out of control		
Want to spend more time with friends		
Thinking about our identity		


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Sexuality

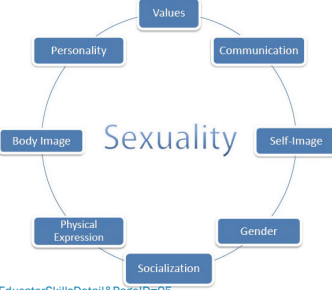


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➤ The exploration of ourselves
❖ our physical bodies, our emotions, self-worth and image, and our interrelations with others


➤ Sexuality is about the importance of personal responsibility in all types of relationships




<http://recapn.etc.org/Recapn/index.cfm?fuseaction=pages.EducatorSkillsDetail&PageID=95>

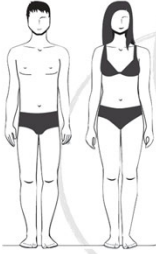
61

Review Of Private Body Parts And Reproductive Anatomy



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- Sexual organs are usually covered, by a **swim suit** or clothing.
- They are considered private.
- These organs are also called **genitals**.


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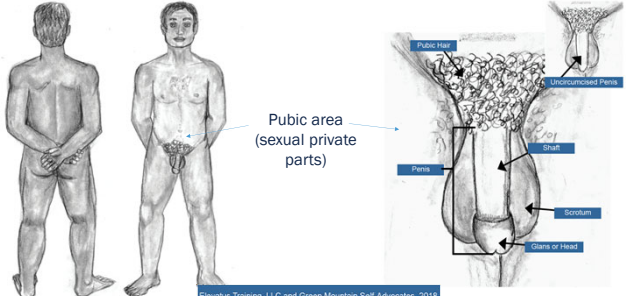
62

Outside Male Sexual Body Parts



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Pubic area (sexual private parts)


Elevatus Training, LLC and Green Mountain Self-Advocates, 2019

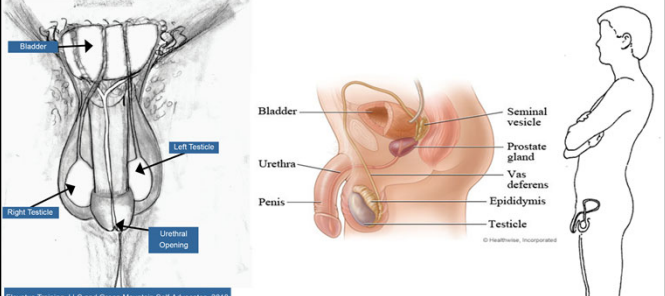
63

Inside Male Sexual Body Parts



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Elevatus Training, LLC and Green Mountain Self-Advocates, 2019

64

How the Male Body Changes During Puberty

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- Testicles begin producing sperm
- Semen is a mixture of sperm and fluid that comes out of the penis
- Erections
- Ejaculation

Semen VS Sperm

Elevatus Training, LLC and Green Mountain Self-Advocates, 2018

65

Outside Female Sexual Body Parts

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The Vulva is the Whole Female Genital Area

Labels: Breasts, Pubic area (sexual private parts), Pubic Hair, Labia, Clitoris, Urethra, Vagina, Anus

Elevatus Training, LLC and Green Mountain Self-Advocates, 2018

66

Inside Female Sexual Body Parts

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Labels: 1. Ovary, 2. Anus, 3. Vagina, 4. Labia, 5. Clitoris, 6. Uterus, 7. Fallopian Tube, 8. Navel (belly button)

Internal labels: Fallopian Tube, Ovary, Uterus, Vagina, Cervix

Elevatus Training, LLC and Green Mountain Self-Advocates, 2018

67

How the Female Body Changes During Puberty

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- An egg travels from the ovaries the uterus every month.
- The uterus prepared for the egg by building a lining of fluids, including blood in its walls
- Menstruation (having a period) is when the blood comes out of the vagina
- Period blood means a woman is healthy and not pregnant
- Periods happen every month and last about 4 to 7 days
- Periods are private

Labels: Fallopian Tubes, Ovary where eggs are, Uterus (womb), Menstrual Flow or Period (womb)

Elevatus Training, LLC and Green Mountain Self-Advocates, 2018

68




69

What are Sexual Body Parts For?

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Most people use their genitals for sexual pleasure and sometimes for reproduction.

Reproduction is the ability to make babies. Although there are now many ways to have a baby, we will talk about having a baby through penis and vaginal intercourse.



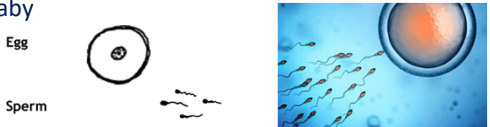
Elevatus Training, LLC and Green Mountain Self-Advocates, 2018

70

Reproduction 101: How Babies are Made/ How a PERSON gets pregnant

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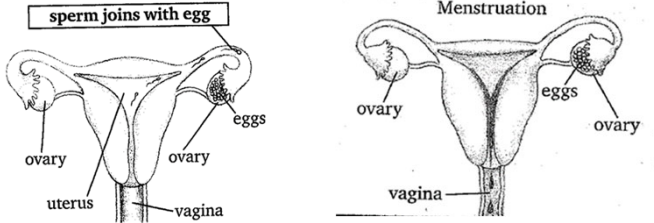
- In males, testes produce sperm
- In females, an egg travels from the ovaries
- It takes sperm from a male and an egg from a female to make a baby



71

Reproduction 101: Sperm Meets Egg (Or NOT)

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- **sperm joins with egg**
- **Beginning of pregnancy**
- **Embryo > Fetus > Baby**


Menstruation

- **No pregnancy**
- **Blood lining in uterus exits vagina (menstruation or period)**

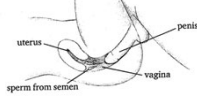
72

Reproduction 101: How Does The Sperm Get TO THE EGG?

Often, a sperm connects with an egg during "sexual intercourse"



Sexual intercourse is a sexual behavior that can include a penis being inserted into a vagina



If semen comes out of the penis into the vagina, the sperm swim to the egg

73

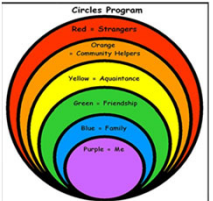
WHERE DO BABIES COME FROM?



<https://www.youtube.com/watch?v=vudZePdQ8B>

74

Circles of Social Relationships



Who would go in each of your circles?
 Can people move from one circle to another?
 How should you act and what could you do with the people in each circle?
 In which circle do boyfriends/ girlfriends go?

Acquaintances, Neighbors, Community Helpers:

- You may shake their hand or wave to them
- Greet and say hello
- Talk about relevant information


Strangers

- Keep your distance from them
- Do not share personal information

75

Social Rules and Safety

- Self-Control
- Rights of Self and Others
 - Respect
 - Rejection - How to handle it
 - Good Decision Making
- Bodily Autonomy
 - Consent
 - Ways in which parenting can contradict education on consent
- Public vs. Private



HOW TO TALK ABOUT CONSENT
 CONSENT IS AN AGREEMENT BETWEEN PEOPLE TO ENGAGE IN SEXUAL ACTIVITY.

I'm not in the mood tonight. OK, want to watch a movie instead?

CONSENT IS ABOUT COMMUNICATION, AND IT SHOULD HAPPEN EVERY TIME. REMEMBER TO ASK CONSENT WHENEVER SEXUAL CONTACT INCLUDES OR CHANGES.

76



77

Learn the Rules

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- Must know the rules in order to teach them
- Rules vary by environment:
 - School
 - Home
 - Community
- Rules vary by relationship:
 - Family
 - Friends
 - Community Helpers
- Know the laws
 - To research your local laws: <https://www.rainn.org/laws-your-state-north-carolina>

Buron, K. D. (2007)
<https://mass.gov/01f04c00b14c7722>

Buron, K. D. & Curtis, M. (2007)
<https://maps.app.goo.gl/2V9H4rYb0r0m06>

78

78

Public vs. Private

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Public and Private Behaviors

Careful or "Yellow" Behaviors:

- It is not quite as personal as a private behavior but we want privacy doing it (e.g., grooming or adjusting clothing).
- Some be careful behavior can be done in public, but only if it is okay to do in that situation. An example is dancing, okay at a dance, but maybe not at a grocery store!
- We need to think about whether other people will be upset if they see us doing these things (e.g., display of affection).

Private or "Red" Behaviors:

- Are only done in a private place with the door shut.
- There is nothing wrong with these behaviors! They are special, but we save them for personal, private times in private places.
- Other people might be embarrassed to see us doing things that are private.
- If we are doing them with another person, we need to make sure that are okay with it happening.

Public or "Green" Behaviors:

- These things can be done in front of strangers.
- They are okay in almost all places.

Public or Private?

Public or Private?

www.elevatustraining.com

79

Create House Rules for your Teen

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DEVELOPMENTAL DISABILITY

- **Clothes/Being Dressed**
 - Where is it Ok to be without clothes on?
 - Where is it Ok to be with just under wear on?
 - Where to get dressed and undressed?
- **Touch**
 - What are the rules about me touching my body?
 - What are the rules about me touching my private parts?
 - Where in the house can I touch my private parts?

80

Decision Making Skills

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- Decision Trees
- Flow Charts
- Social Behavior Maps

The diagram is a decision tree starting with the question "Will I be sexually active?". It branches into "No" and "Yes". From "No", it asks "How will I handle being around it?", "How will I communicate my choices?", and "Where will I draw the line?". From "Yes", it asks "How often?", "Under what conditions?", and "What steps will I take to protect myself?".

<https://images.app.goo.gl/uH5mmMe2sHsvRcv7>

Social Behavior Mapping

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Winner, M. G., Bosmeijer, J., & Horras, J. (2007). *Social behavior mapping*. San Jose, CA: Think Social Publications.
www.socialthinking.com

CHAT ROOM SAFETY ON THE INTERNET Behaviors That Are EXPECTED			
Expected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Only share the truth if it's necessary.	• Helps to draw the lines.	• People's behavior is not only about the truth.	• Good.
• Avoid talking to strangers.	• Avoid talking to the wrong or the wrong person.	• Avoid talking to the wrong or the wrong person.	• Good.
• Do not send photos of yourself or others.	• Do not send photos of yourself or others.	• Do not send photos of yourself or others.	• Good.
• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Good.

CHAT ROOM SAFETY ON THE INTERNET Behaviors That Are UNEXPECTED			
Unexpected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Do not talk to strangers.	• Do not talk to strangers.	• Do not talk to strangers.	• Bad.
• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Bad.
• Do not send photos of yourself or others.	• Do not send photos of yourself or others.	• Do not send photos of yourself or others.	• Bad.
• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Do not give out your address or phone number.	• Bad.

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DEALING WITH YOUR PERIOD Behaviors That Are UNEXPECTED

Unexpected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Not having a day that your cycle is due.	• Surprised	• You freak out.	• Scared
• Not being prepared. Do not have any tampons or pads.	• Annoyed	• You have to ask others for a tampon, or call your mom.	• Embarrassed
• If a group of people, getting up and wanting that you have started your period.	• Grouched out	• Others have weird thoughts about you because people are not prepared to know you have your period.	• Bad
• Locally asking people if they have a tampon or pad.	• Embarrassed	• You get blood on your clothes.	• Upset
• Not bothering to go and check yourself.	• Disgusted	• Most months it happens again and you are not prepared again.	• Mean
• Not putting on a sanitary napkin (or tampon).	→	→	→
• Not marking on a calendar when your cycle begins and ends.	→	→	→
• If you bleed through your pants, you don't change them.	→	→	→
• Don't change your underwear if you are using a napkin.	→	→	→

DEALING WITH YOUR PERIOD Behaviors That Are EXPECTED

Expected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Plan ahead. Know what day you are supposed to start your period.	• Prepared	• You will not be surprised.	• Good
• Be prepared. Have tampons or sanitary napkins with you in your pants or backpack.	• Comfortable	• This will not have to do others if they were one that you could have. You will not get your clothes messy.	• Clean
• If you think you might be bleeding without pads, and you are in a group of people, simply get up, say, "Excuse me" and go to the bathroom to check yourself.	• Thankful	• Nobody had you. You will be.	• Calm
• If you don't have a tampon or napkin, ask another girl for them by whispering the question. "Can I borrow a tampon?"	• Respected	• You will feel clean and confident.	• Responsible
• Go to the restroom and change your pants or tampon often on the first day of your period. This could be every two hours.	→	→	→
• Do not substitute to everyone what your underwear are. This is a personal and private matter.	→	→	→
• Bring the tampon or napkin to a toilet paper and place in the waste container.	→	→	→
• Mark on a calendar the first day of your cycle and the last day of your cycle to help you be prepared for next time.	→	→	→
• Change your pants if you bleed through them. You may need to call home for clean pants, or it is a responsibility around your waste, to take the trash.	→	→	→
• Change underwear daily.	→	→	→

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IF YOU HAVE ACNE Behaviors That Are UNEXPECTED

Unexpected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Do not wash your face.	• Grouched out	• More will end up to wash your face.	• Mad
• Do not apply acne medicine.	• Surprised	• Others will tell you that you should use medicine, or they will think it.	• Embarrassed
• Pick at your pimples.	• Embarrassed	• Others will be embarrassed to hang out with you.	• Sad
• Pop your pimples.	• Unfriendly	• Others may tell you that you should not touch your face.	• Left out
• Scratch your pimples.	→	→	→
• Eat foods that are high in fat such as fried foods.	→	→	→
• You end up with facial scars.	→	→	→

IF YOU HAVE ACNE Behaviors That Are EXPECTED

Expected Behaviors	How They Make Others Feel	Consequences You Experience	How You Feel About Yourself
• Wash your face once in the morning and once in the evening before bed.	• Calm	• More does not pop you.	• Happy
• Do not pop pimples.	• Happy	• People are not embarrassed to hang out with you.	• Clean
• Do not pick pimples.	• Proud	• People are proud to be your friend.	• Calm
• Do not scratch pimples.	→	→	→
• Ask your doctor for possible medicine.	→	→	→
• Eat healthy foods.	→	→	→
• Drink plenty of water.	→	→	→

Teachable Moments

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89

Teachable Moment Format

Answering Questions

- Reassure the person that it is good to ask questions
- Find out what the person thinks/is really asking
- Decide what "messages" you want to give
- Answer simply, using correct vocabulary
- Encourage the person to give you feedback

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90

Teachable Moments

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Q. What's that? (pointing to a woman's breast or other body parts)

A. That's a breast. Women have breasts. Men don't. Would you like to know anything else about that?

Q. How come I have a penis and you don't?

A. Boys have penises and girls have vulvas. I'm a woman — a girl who is all grown up — so I have a vulva instead of a penis. And you're a boy, so you have a penis instead of a vulva.

Q. Do boys have periods?

A. No. Only women have periods. What do you know about periods?

91

Teachable Moments cont.

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Responding to Behaviors and Comments

- Decide first if it is better to ignore the situation. If ignoring the situation is inappropriate, then continue with the following steps...
- Name the behavior/comment to the person(s) as you see or hear it; praise if appropriate
- Find out the meaning of the behavior/comment to the person(s)
- Decide what "messages" you want to give
- Give the messages by responding simply
- Encourage the person(s) to give you feedback

92

Teachable Moments cont.



- Your child and his/her friend are giggling in the bedroom. You open the door to see what is funny and find them both looking at a photo of a naked woman on friend's phone.
- How do you respond?

93

Teachable Moments cont.



- Your 14 year-old daughter has recently begun having her period. One day when she returns from school, you see blood on her pants.
- How do you respond?

94

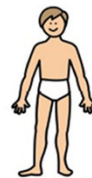
Teachable Moments cont.



- While you are at the grocery store, you see your son hug the store clerk.
- How do you respond?

95

Visual Supports



My private parts are covered by my underwear



96

Social Story about when it is okay to talk about sex

<https://www.boardmakeronline.com/Activities/CommunityActivities>

101

STI Sorting Activity

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<https://www.boardmakeronline.com/Activities/CommunityActivities>

102

Augmentative and Alternative Communication (AAC)

<https://www.boardmakeronline.com/Activities/CommunityActivities>

103

Augmentative and Alternative Communication (AAC)

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www.mytobidynavox.com/Store/ShopCoreFirst

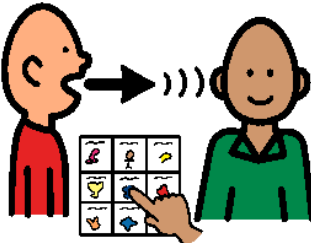
Vocabulary for HEALTH AND BODY PARTS

104

Aided Language Stimulation:
What It Is and Why We Should Use It

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“Aided Language Stimulation is a teaching strategy in which the facilitator highlights symbols on the user’s communication display as they interact and communicates verbally with the user.”




(Goosens', Crain & Elder, 1988)


105

Input **Output**

Spoken language development



Child learning aided symbols




Gayle Porter, 2004

106

Input **Output**

Child learning aided symbols



Images: Joan Cafiero, 2004 via Tannish & Farrall, 2013

107

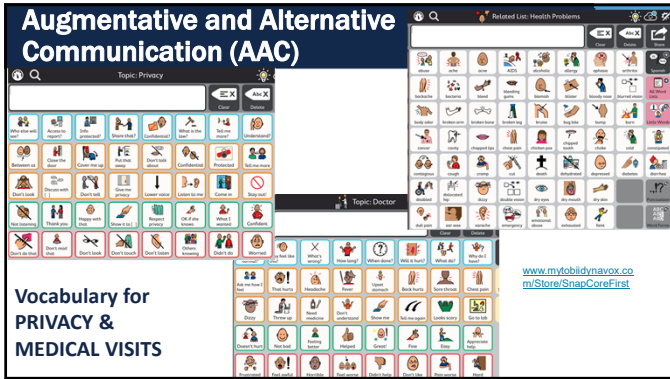
Aided Language Stimulation Is...

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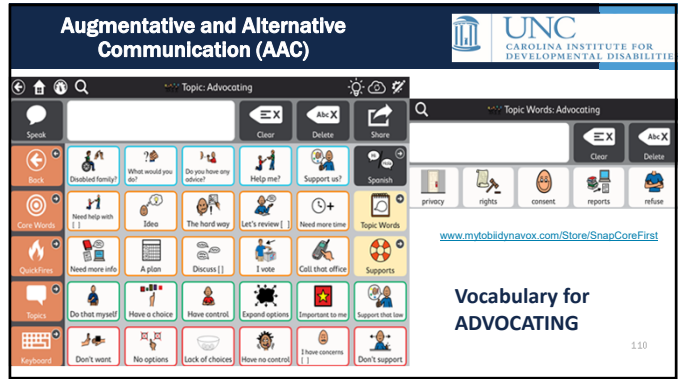
“Based on the premise that by watching symbols being used extensively by others in natural interactions, the user will begin to *establish a mental template* of how symbols can be combined and recombined generatively to mediate communication during the activity”

(Goosens' et al., 1992, p. 101)

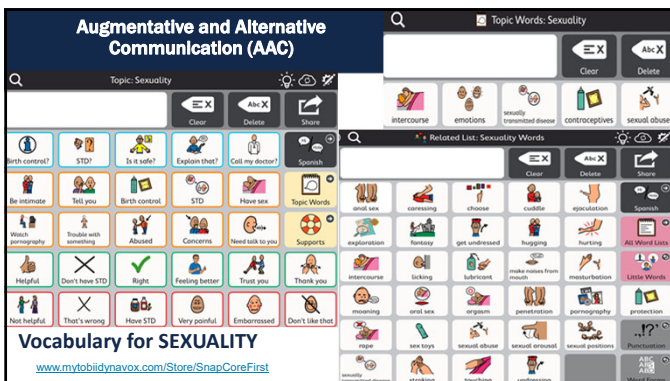
108



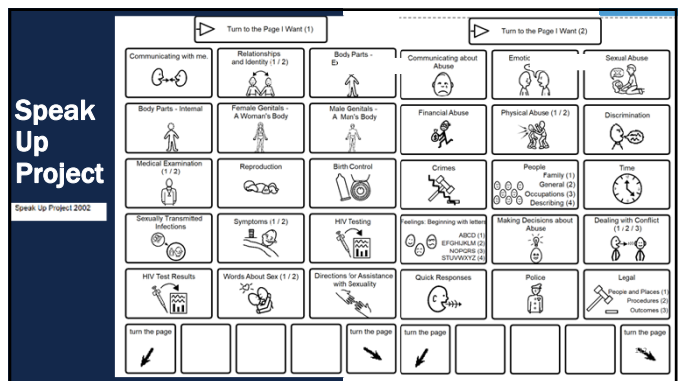
109



110



111



112

If a survivor discloses to you:

- Contact your county's Department of Health and Human Services <http://www.ncdhhs.gov/dss/local/index.htm>
- Prevent Child Abuse North Carolina **1-800-CHILDREN**
- RAINN (Rape, Abuse & Incest National Network) is nation's largest anti-sexual violence organization www.rainn.org or **800-656-HOPE**
- National Child Abuse Hotline: **1-800-4-A-CHILD**
- NC Rape Crisis Centers (RCC): <https://nccasa.org/get-help/>
- North Carolina Coalition Against Sexual Assault (NCCASA): <http://www.nccasa.org/>
- Family Physician, Pediatrician
- Mental Health Center or Health Department

117

QUESTIONS?



118

Carolina Institute for Developmental Disabilities

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 Campus Box #7255
 Chapel Hill, NC 27599-7255
www.ciddd.unc.edu

Margaret DeRamus, MS, CCC-SLP: Margaret.DeRamus@ciddd.unc.edu
 Morgan Parlier, MSW, LCSW: Morgan.Parlier@ciddd.unc.edu



119

Sexual Health Education Resources for Individuals with IDD

- ❖ Elevatus Training: www.elevatustraining.com
- ❖ Healthy Bodies: <https://vkc.vumc.org/healthybodies/>
- ❖ OAR Sex Ed for Self-Advocates: <https://researchautism.org/sex-ed-guide/>
- ❖ Sexuality for All Abilities: <https://madhatterwellness.com/sexuality-all-abilities/>
- ❑ Mad Hatter Wellness Videos: <https://madhatterwellness.com/sexuality-all-abilities/>
- ❖ National Council on Independent Living (NCIL): <https://ncil.org/sex-ed-for-individuals-with-idd/>
- ❑ NCIL YouTube: <https://ncil.org/sex-ed-for-individuals-with-idd/>
- ❖ Birds and the Bees: <https://asdsxed.org/category/curriculum/>
- ❖ Scareleteen: <https://www.scarleteen.com/article/disability>
- ❖ Let's Talk How: <http://lets-talk.how/teen-talk-adapted-for-all-abilities>
- ❖ Respectability: <https://www.respectability.org/resources/sexual-education-resources/>
- ❖ Oak Hill Positive Choices: <https://relationshipandsexuality.oakhillct.org/positive-choices/>
- ❖ F.L.A.S.H.: <https://kingcounty.gov/depts/health/locations/family-planning/education/FLASH/special-education.aspx>
- ❖ SEICUS: <https://siecus.org/resources/comprehensive-sex-education-for-youth-with-disabilities/>
- ❖ Sexuality Resource Center for Parents (SRCP): http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

120

SHE Books for Teaching Individuals with IDD

- *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality.* Terri Couwenhoven. Woodbine House. 2007
- *The Boy's Guide to Growing Up: Choices and Changes During Puberty.* Terri Couwenhoven. Woodbine House. 2012
- *The Girl's Guide to Growing up: Choices and Changes During the Tween Years.* Terri Couwenhoven. Woodbine House. 2012
- *I Opens: Parents Ask Questions About Sexuality and Children with Developmental Disabilities.* Dave Hingsburger. Family Support Institute Press. 1993
- *Sexuality: Your Sons and Daughters with Intellectual Disabilities.* Karen Melberg Schwier and David Hingsburger.
- *Just Say Know: Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities.* Dave Hingsburger. Diverse city Press, Inc. 1995
- *It's So Amazing.* Robie Harris, Candlewick Press, 1999
- *It's Perfectly Normal.* Robie Harris, Candlewick press, 1994
- *Changing Bodies, Changing Lives.* Ruth Bell, Three Rivers Press, 1998

121

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122

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123

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124



125