Healthy Sexuality for Adults with Down Syndrome

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Adult Down Syndrome Center

Park Ridge, IL

Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, communitybased health care services.



Disclaimer

This information is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health or behavioral evaluation, diagnosis or treatment plan by a qualified professional.

Today's agenda

- In supporting individuals with sexuality education, you will learn...
 - Why it is important.
 - What needs to be learned.
 - How best to teach it.
- We will go over case studies and practice scenarios.
- Resources will be shared.



The Why

Benefits of sexuality education

- More responsible sexual behavior.
- Learn essential skills in social etiquette and self-care.
- Reduces inappropriate sexual expression.
- Increases pride, confidence and self-acceptance.
- Aids in the development of a personal sexual identity.
 Facilitates healthy sexual development.
- Helps recognize inappropriate sexual advances and be able to report incidents of suspected sexual abuse.

Benefits of parents as the primary sexuality educators

- **Decreases sexual risk behavior** as well as improved the parent-child relationship (Klein et al., 2005).
- Facilitates healthy sexual development (Bundy & White, 1990).
- Adolescents who have repeated communication about sex, sexuality, and development with their parents are more likely to have an **open** and closer relationship with them, in addition to being more likely to talk with their parents in the future about sexual issues (Martino et al., 2008).
- Parents can individualize what they teach based on their family life, their values, their child's needs at the time, and modify the content so their child understands. They can model appropriate behavior and supervise their child's comprehension (Jaccard et al., 2002).

Sexuality education and people with Down syndrome

- 73% of parents reported their child received sexuality education in the classroom setting, primarily a mainstream health class.
- 85% of parents reported previously initiating home-based sexuality education, however not with adapted materials.
- Parents understand the importance of sexuality education but lack the comfort and confidence in talking about it.
- Parents reported being more hesitant talking to their child with Down syndrome about sexuality topics compared to their other children.

Barriers

Parent-reported

- Unsure of how to approach the topic.
- Uncomfortable with their own sexuality or sexuality of their loved one.
- Fear of exploitation.
- Fear of arrest/legal problems.
- Social appropriateness.
- What the future holds.

Staff-reported

- Negative attitudes about sexuality and people with disabilities.
- Lack of training.
- Lack of support/resources from employer or parents.
- Lack of consent to teach from parents/guardians of constituents.
- Lack of policies about sexuality and sexuality education by employment agency.

Family reported topics of concern

Adolescent only themes

- Grooming and hygiene
- Socially appropriate behavior

Combined themes

- Privacy
- Modesty
- Boundaries
- Consent
- Safety
- Healthy
 relationships
 Intimate self-care

Adult only themes

- Family dynamics
- Contraception
- Pregnancy

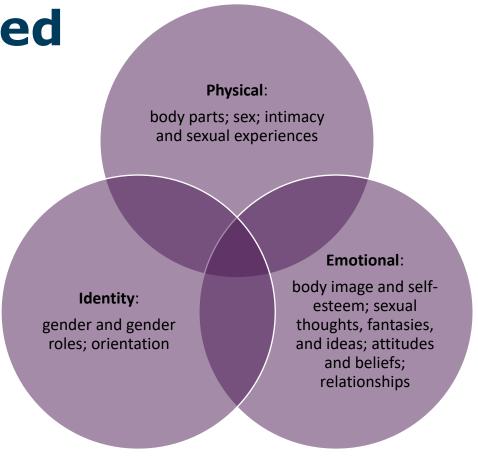
Frank & Sandman, 2021



The What

Sexuality defined

Sexuality is an integral part of who we are, what we believe, what we feel, and how we respond to others.



Sexuality topics to consider

Human development Dating and relationships

Sexual activity

Sexual health

Pregnancy

Rights and responsibilities

Human development topics

- Identification of sexual body parts
- Puberty
- Physical differences between males and females
- Privacy of the body
- Feelings of arousal
- Grooming/hygiene
- Self-esteem
- Body changes as one ages

Dating and relationships topics

- Types of relationships
- Crushes
- Alternate sexual identities
- Boundaries
- Who to date
- Planning a date
- Handling rejection
- Healthy vs. Unhealthy relationships
- Breaking up
- Consent
- Marriage
- Socially appropriate behavior

Sexual activity topics

- Kissing
- Touching
- Foreplay
- Intercourse
- Safety
- Consent

Sexual health topics

- Use of contraception
- Sexually transmitted infections (STIs)
- Menstruation
- Masturbation
- Wet dreams
- Erections
- Sexual health exams
- Menopause

Pregnancy topics

- How it happens
- Body changes
- Giving birth
- Raising a child

Rights and responsibility topics

- Laws and consequences
- Consent
- Exploitation and abuse
- Responsibilities of marriage
- Responsibilities of parenting

Specific topics for healthy relationships

Social Conflict Social skills boundaries resolution Handling Understanding Dating skills rejection emotions Abuse **Intimacy** Consent



The How

Role of parents/staff

- 1. Acknowledge your attitudes about sexuality and disability.
- 2. Communicate your values. (parents only)
- 3. Recognize sexuality as a healthy and positive aspect of being human.
- 4. Share information.
 - Teach how the individual learns best.
 - Provide opportunities to practice new skills.
 - Use teachable moments.
 - Be a role model.

Ways to approach sexuality education

Planful approach

When a situation involving sexuality or sexual behavior arises, the parent/disability service provider takes the initiative and uses the **opportunity to teach** instead of punish or scold. Being planful creates a learning experience for everyone involved, leading to improved communication and knowledge.

Reactive approach

When a situation involving sexuality or sexual behavior arises, the parent/disability service provider responds to the situation by restricting, punishing or limiting the behavior or communication.

This response contributes to a negative message about sexuality and sexuality education.

Example of a reactive approach

Mike is caught masturbating by a service provider in the hallway at his day program.

Staff at the day program are mortified and...

- Yell at him to stop touching his penis.
- Everyone else in the hallway stops, stares, and laughs at him.
- You shame him and send him to talk to the building administrator and say he is going to get in trouble.
- You also tell him his parents/staff are going to be so mad and disappointed in him when they find out.

At home...

- You ground him when he comes home, or staff restricts his community outings and takes away his phone.
- He feels shamed for doing something that is natural.
- He does not understand why what he did was wrong.

Example of a planful approach

Mike is caught masturbating by a service provider in the hallway at his day program.

Staff at the day program can...

- Talk with Mike about the concepts of private and public.
- Mention touching your penis is something that should be done in private.
- Confirm everything at the day program is considered a public space, even the bathrooms.
- Say he can talk with his parents/staff at group home about where he can masturbate at home.
- Send home visual supports on the topics discussed

At home...

- Review content sent home by the day program and review public and private.
- Tell him that he can masturbate/touch his penis at home in his bedroom or bathroom because those are private areas.
- If he has questions, he can talk with you, group home staff, or another trusted adult about them.

Learning styles

Visual

 These learners need to "see" the information or material in one form or another.

Auditory

 These learners are likely to learn best when hearing the information.

Motor

 These learners need to do an activity, practice a skill or manipulate material physically in order to learn most effectively.

Learning strategies

VISUAL	AUDITORY	MOTOR
 Visual supports like pictures or schedules Social stories Demonstration Movies/videos Written materials with lots of graphics 	 Verbal praise Verbal prompts Listen to a social story Reading out loud Group discussion 	 Practice/Experiment Role play Model behavior Write Play a game

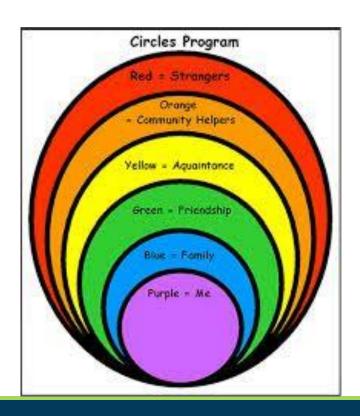
Case study

At work, the boss is concerned that your young adult with DS is having trouble with personal boundaries and has been touching peers "inappropriately." Basically, hugging co-workers and customers. The boss does not want your child to be fired for this behavior. You have recently noticed similar behaviors when you are with your child in public.

Learning strategies

VISUAL	AUDITORY	MOTOR
•A social story on hugging/appropriate touch.	 Verbal praise when they touch appropriately ("good job"). 	Practicing appropriate touch.Different typesDifferent relationships
 Demonstrating appropriate touch (both the type of touch as well as where to touch) for different 	Verbal prompts when they touch inappropriately ("quiet hands").	Model appropriate touch.
people.	 Listen to/read a social story about hugging. 	• Role play.
 Have a picture of people they can hug and/or pictures of "Strangers" with an X through them. 	• Circles Curriculum.	Write a list of people they can hug.Circles Curriculum.
Circles Curriculum.		

Circles curriculum©

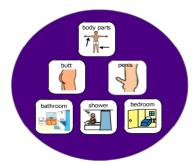


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The ME Circle



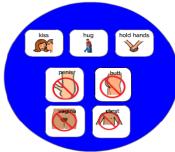


I can touch all of my body parts.

I can touch my private body parts in private spaces (like my bedroom and my bathroom at home).

The FAMILY Circle





I can kiss, hug, and hold hands with my family including my parents, siblings, aunts, uncles, and cousins.

I do NOT touch my family's private parts and they do NOT touch mine without my permission.

The FRIENDS Circle





I can side hug, fist bump, far away hug, high five, shake hands, and wave to my friends.

I do NOT kiss my friends or hug them closely.

I do NOT touch my friends' private parts and they do NOT touch mine.

Sample video on appropriate touch

Appropriate Touch

Appropriate Touch for People in My Life









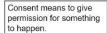




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Consent

- Give permission
 - It is ok to change our mind. We can give permission and take it away.
- In a relationship both people must give permission
 - To be boyfriend/girlfriend
 - Touching our body and how they may touch it
 - Hold hands, put arm around, hug, kiss, etc.
 - Seeing our body
- If someone touches you without your permission, talk to a trusted adult.





My consent is important to decide who will see the private parts of my body.



The law says children can NOT give consent for

intimate behavior.



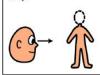
It is NOT consent when someone threatens or forces you to do something sexual you do not want to do.



It is ok for me to change my mind after I give consent.



My consent is important to decide if I will see or touch another person's body.



Intimate behavior without consent is against thelaw.



If I have questions about consent I can ask my parents.



That means I can say yes one time and say no another time.



Other people can give consent too.



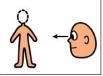
If this happens you or your parents can report it to the police.



I will NOT get in trouble if I change my mind.



The other person gets to choose if I can see or touch his or her body.



It is NOT consent if someone asks you to keep a secret about intimate behavior.



My consent is important to decide who will touch my body.



For intimate behavior to happen both people need to give permission.



It is NOT consent when someone gives you gifts, money, or treats to get you to do something sexual you do not want to do.

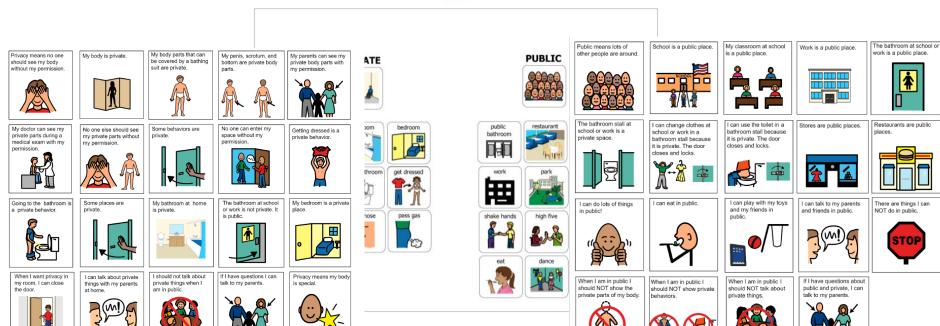


Story about Consent

Public and private

PRIVATE VS. PUBLIC

FEMALE



Story about Privacy for Boys

Story about Public

Body changes







Soon I will have

to grow. I will need

Sometimes I might

feel proud.



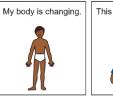














I will have hair near



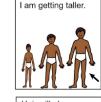








These changes





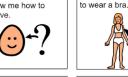
bov.







I can ask my mom or another female to show me how to

















Sometimes I might

feel proud.



I might grow hair





Sometimes I might feel embarrassed about these changes.



If I have questions. I can ask my parents.



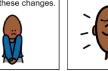
My parents love me and they understand.



These changes happen to all boys.



Sometimes I might feel embarrassed about these changes.



If I have guestions, I can ask my parents.



My parents love me and they understand.



Story about Body Changes for Girls

Story about Body Changes for Boys

Menstruation

Story About Getting My Period





It may last 4 to 7 days







need a hygiene product

During my period I may

like a sanitary pad. tampon, or period panties.





Menstruation is private.



questions about

menstruation, she can

help me decide which

hygiene product is best for me to use.







When I get my period I

will see blood in my

underpants.













Story About When to Change My Menstrual Hygiene Product







I will change my hygiene

product at lunchtime.

I use hygiene products like





I need to change my

















Finally, I will change my hygiene product when I get ready for bed.



I will let my mom know if there is blood in my underwear so she can help me wash it out. I will also need to tell her about my used period panties.

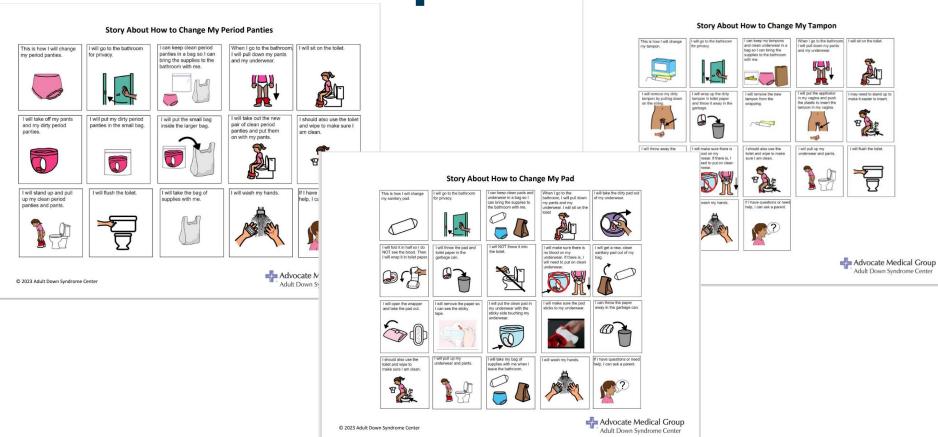


If I have questions, I can talk to a parent.



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Menstruation products



Masturbation

My special private time



NO ONE should see My bedroom is a me touch my private private place.



parts.



If Mom or Dad It is ok for ME to knocks on my door. touch MY OWN I can say, "I'm busy." penis and testicles.



Touching myself is one way I can make myself feel good. And that is ok!



My body is mine.



My bathroom at home is a private place.

I can touch myself.



If my penis feels sticky. I can clean it off with a towel or



I put my clothes on and wash my hands when I am done.

Some touches feel

I will close the door

so I can have privacy.

very good.



If I have guestions. I can talk to my Mom and Dad about my special private time.

Touching my private

when I am alone.

parts is something I do

I like to touch my

private parts.



My special private time.



My bathroom at home is a private place.



When I have an erection. I can touch my penis.



I can touch my penis while it feels good. It may take a few minutes.



It is ok for MF to touch MY OWN penis and testicles.



I will close the door so I can have privacy.



I take off my clothes when I want to masturbate



A little sticky liquid might squirt out of my penis. This is ok. It is not pee. It is semen.



NO ONE should see me touch my private



Touching my private parts is something I do when I am alone.



I hold my penis and move my hand up and down the shaft.



I will wipe my penis when I am done.



It is NOT ok to rub or touch my private parts in front of others even if I have my clothes on



My bedroom is a private place.



My penis may get big

If Mom or Dad knocks on my door. I can say, "I'm busy,"



to help if it hurts to

touch my penis.

and firm. This is called an erection. It is ok. It will get soft again!



I can use a lubricant I can look at pictures or a movie to help me think sexy thoughts.



I put my clothes on and wash my hands.



If I have questions, I can talk to my Mom or Dad about my special private time.



Story about How to Masturbate-Male

Menopause

MENOPAUSE



happen to all women as they get older.



I may get hot during the day. This is called a



I may gain weight.































My body will change.

Or I may not have

I may not sleep well

at night.

symptoms at all.



MENOPAUSE AND HOT FLASHES













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like my family, staff, or



My face may turn red.

Hot flashes may only

last a few minutes.











Orientation vs. Identity

Sexual orientation

Attraction to other people

- Straight
- Gay
- Lesbian
- Bisexual
- Asexual
- Pansexual

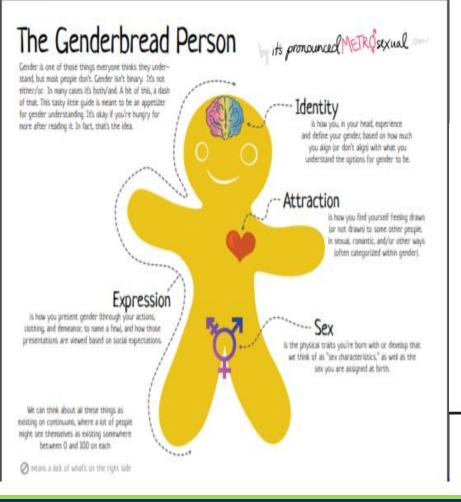
Sexual/Gender identity

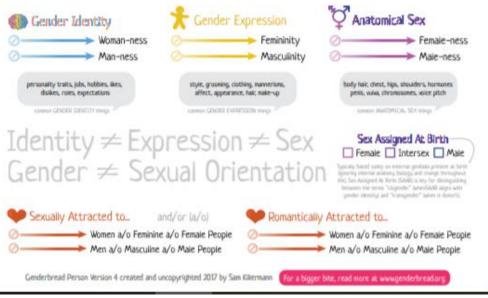
How individuals perceive themselves and what they may call themselves. It may be the same or different from the sex assigned at birth.

- Male
- Female
- Nonbinary

Use pronouns to help with identity

- she/her
- he/him
- they/them





https://www.genderbread.org/

Social skills

Why are conversation skills important in romantic relationships?

They help us communicate!

- Get to know someone.
- Help to plan a date.

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- Help to have conversations when we are on a date.
- Help us share our feelings.
- Help us say what we want and do not want in the relationship.

My Rules for Conversation I will look at the person talking and I will listen to what others are I will maintain good personal space. I will speak in a loud and clear voice. I will wait my turn to speak. I will talk about what everyone else is talking about. I will ask questions when I am confused.



COMPROMISE

What does it mean?

- Not always getting your way.
- Doing something that is not your idea.

Compromise...

- Requires flexible thinking.
- Is a skill that helps us develop & maintain healthy relationships.



WHAT SHOULD JACOB & CRISTINA DO? Compromise 2

Compromise 1

Do one thing that they both want to do.



Jacob





Time 1



Do one of their choices this time and the other person's choice the other time.

Time 2

Cristina



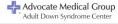
Decide together to do something that is not either of their first choices.

Compromise 3





Jacob AND Cristina



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Social skills

Sharing touch and affection

Types of touch and affection

Hugging



Holding hands



Kissing



Rules for sharing touch and affection

- Know your boundaries.
 - · What types of touch and affection are you comfortable sharing?
- Talk with your partner about their boundaries.
 - · What types of touch and affection are they comfortable sharing?
- Respect each other's boundaries.
- Avoid public displays of affection (PDA)!
 - · PDA is demonstrating a private behavior in a public space.

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HANDLING REJECTION



- · Yes. We do not always get what we want
- It is OK for someone to tell me "No"
- . It is OK for me to say "No"

How to handle rejection:











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Social skills

How to Plan a Date



Cristina

Jacob

In this booklet, Cristina and Jacob help us learn what we need to think about when planning a date.



Ingredients for a successful relationship



- Be open and honest.
- Listen to each other.
- Say nice things.
- Apologize.
- Share your feelings appropriately.

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 Arguments can happen. · Once the argument is over, do not keep bringing it up.

- Respect boundaries.
- Share touch and affection appropriately.
- Do nice things for each other.
- Compromise and take turns.

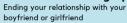
Healthy Safe

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Happy

What is breaking up?

BREAKING UP





People break up when...

- They do not want to spend time together
- · They no longer have romantic feelings



How to break up

- Meet up or call the person
- · Say "I am breaking up with you because..."
- · Tell them why



How to feel better

















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Things to remember

- Sexuality is a right.
- Sexuality is a very broad topic.
- Parents play an important role in the sexuality education of their children, especially those with DS.
- Be planful!
- Teach the way the person learns best!
- It is ok to ask for help!

Resources

- Healthy Relationship Workbook by The Arc of Spokane- http://www.arc-spokane.oResrg/Healthy%20Relationship%20Workbook.pdf
- Healthy Relationships Toolkit by Vanderbilt Kennedy Center https://vkc.mc.vanderbilt.edu/healthybodies/

Resources cont.

- Family Life and Sexual Health by King County Dept. Public Health http://www.kingcounty.gov/healthservices/health/pers-onal/famplan/educators/SpecialEducation.aspx
- Sexuality and Disability: A Guide for Parents by Alberta Health Services http://www.srcp.org/pdf_versions/Alberta.pdf
- Planet Puberty
 https://www.planetpuberty.org.au/

Resources cont.

TeachABodies dolls

https://teach-a-bodies.com/

· Circles Curriculum

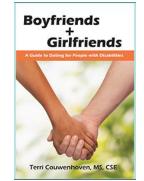
https://stanfield.com/product/circles-curriculum-bundle-w1004-38/

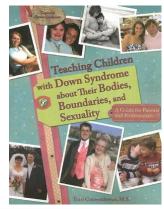
Life Horizons Curriculum

https://stanfield.com/product/life-horizons-family-life-program/

Resources cont.

- Boyfriends and Girlfriends by Terri Couwenhoven
- Teaching Children with Down Syndrome about their Bodies, Boundaries, and Sexuality by Terri Couwenhoven
- What is sex? A Guide for People with Autism, Special Education Needs, and Disabilities- Healthy Loving, Healthy Living by Kate Reynolds







Videos

- Amaze.org
 - AMAZE Org YouTube
- National Council on Independent Living
 - Sex Ed for People With I/DD. YouTube

References

- Ballan, M. (2001). Parents as sexually educators for their children with developmental disabilities. *SIECUS Report*, 29(3), 14-19.
- Bundy, M. L., & White, P. N. (1990). Parents as sexuality educators: A parent training program. *Journal of Counseling & Development*, 68, 321-323.
- Couwenhoven, T. (2007). Teaching children with Down syndrome about their bodies, boundaries, and sexuality. Bethesda, MD: Woodbine House.
- Frank, K. & Sandman, L. (2021). Parents as the primary sexuality educators for adolescents and adults with down syndrome: A mixed methods examination of the home B.A.S.E. for intellectual disabilities workshop. *American Journal of Sexuality Education*. https://doi.org/10.1080/15546128.2021.1932655
- Gomez, M. T. (2012). The S words: Sexuality, sensuality, sexual expression and people with intellectual.
- Jaccard, J., Dodge, T., & Dittus, P. (2002). Parent-adolescent communication about sex and birth control: A conceptual framework. New Directions for Child and Adolescent Development, 97, 9-35.
- Klein, J. D., Sabaratnam, P., Pazos, B., Auerbach, M. M., Havens, C. G., & Brach, M. (2005).
 Evaluation of the parents as primary sexuality educators program. *Journal of Adolescent Health*, 37, S94-S99.
- Martino, S. C., Elliott, M. N., Corona, R., Kanouse, D. E., & Schuster, M. A. (2008). Beyond the "big talk":
 The roles of breadth and repetition in parent-adolescent communication about sexual topics.
 Pediatrics, 121, e612-e618.

Highlighted resources

Social Skills

https://adscresources.advocatehealth.com/resources/?category=Social%20Skills

Puberty, Sexual Health, and Relationships

https://adscresources.advocatehealth.co m/resources/?category=Puberty%25c%2 5%20Sexual%20Health%25c%25%20and %20Relationships



I'm looki

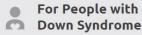
COVID-19 Resources

Review articles, resource lists, and videos related to COVID-19 and Down syndrome.

Adult Down Syndrome Center | Resource Library











Events, Classes & Programs See the Schedule



Video Gallery View All



Related
Organizations
See Listing of Links



Project

Resources: adscresources.advocatehealth.com

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resources

Instagram: instagram.com/adultdownsyndromecenter

Email newsletter: eepurl.com/c7uV1v



email newsletter



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