Supporting Healthy Sexuality for Individuals with Down Syndrome

April 22, 2023 Katie Frank, PhD OTR/L

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.

(Ballan, 2001; Couwenhoven, 2007; Gomez, 2012)

Benefits of parents as the primary sexuality educators

- **Decreases sexual risk behavior** as well as improved the parentchild 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).

Attitudes...true or false?

- It is best to wait for the individual with DS to raise questions about sexuality before discussing the topic with him/her.
- Sex education for individuals with DS has a valuable role on safeguarding them from sexual exploitation.
- Individuals with DS can have safe, healthy relationships with individuals without a disability.
- Parents of adults with DS should be informed of all medical issues including reproductive and sexual ones.
- Sterilization should be used as a means of inhibiting sexual desire in individuals with DS.
- In general, sexual behavior represents a major problem area in management and caring for adults with DS.
- People with DS are less likely to identify as non-heterosexual (LGBTQ+) than the general population.

Myths about sexuality and people with I/DD

- Are asexual.
- Have decreased needs for touch and affection.
- Do not recognize pleasure or the expression of love.
- Lack self-confidence.
- Do not get sexually assaulted.
- Do not need sex education.
- Should only marry and have sexual relationships with other people with I/DD.
- Should not have children.
- Do not identify as anything other than heterosexual.

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.



The What

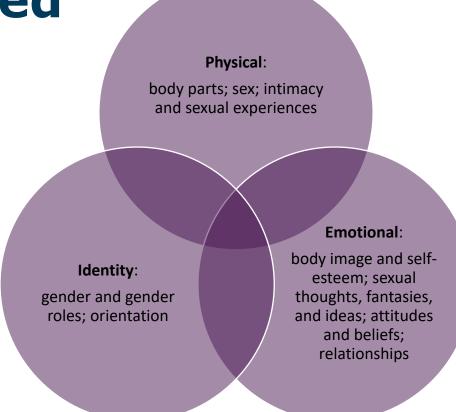


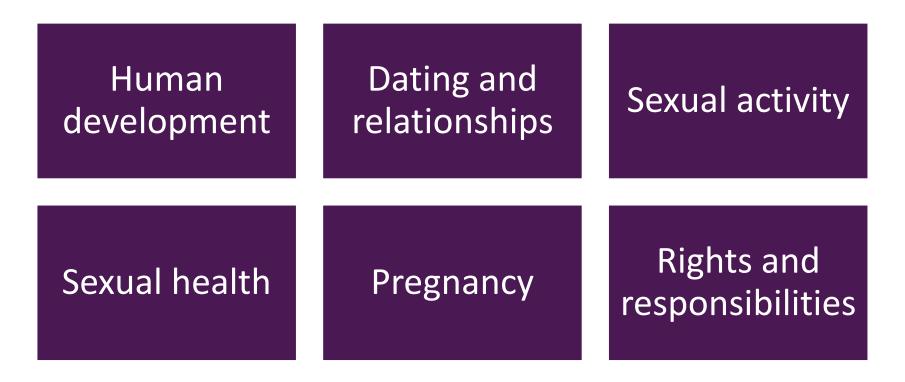




Sexuality defined

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





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



- 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



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



- Use of contraception
- Sexually transmitted infections (STIs)

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- Menstruation
- Masturbation
- Wet dreams
- Erections
- Sexual health exams

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



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

Specific topics for healthy relationships



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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.

Core concepts

- COMMUNICATION
 - **Communication** should be a 2-way street. There should be opportunities for all participants (family/staff and individuals with DS) to ask questions, provide feedback, and express their values.

RESPECT

 Having an attitude of **respect** that shows respect for yourself and the person with DS as well as a respect for the rights previously mentioned.

• SAFETY

 Creating a safe space allows for questions and recognizes that there are no wrong or bad questions. It avoids shaming or blaming in thoughts and statements. Remember nonverbal cues (voice, tone, body posture) should be open and relaxed.

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 planful approach

A parent of an adolescent boy with DS is called by the principal because her son was found playing with his penis in the classroom. Mom tells the principal she will take care of it when he comes home.

You can ...

- Talk with Mike about the concepts of private and public.
- Mention touching your penis is something that should be done in private.
- Identify everything at school is considered a public space, even the bathrooms.
- Tell him that he can talk with you about masturbating/touching his penis at home in his bedroom or bathroom because those are private areas.

Example of a reactive approach

An adolescent boy with DS is found playing with his penis in the classroom.

At school...

- -The teacher yells at him to stop touching his penis.
- -Everyone else in the classroom stops, stares, and laughs at him.
- -The teacher tells him his parents are going to be so mad and disappointed in him when they find out.
- -You shame him and send him to the principal's office

At home...

- -You ground him when he comes home. -He feels shamed for doing something that is natural.
- -He does not understand why what he did was wrong.

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 style examples-Visual

- Visual supports like pictures or schedules
- Social stories
- Demonstration
- Movies/videos
- Written materials with lots of graphics

Learning style examples-Auditory

- Verbal praise
- Verbal prompts
- Listen to a social story
- Reading out loud
- Group discussion

Learning style examples-Motor

- 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.

VISUAL	AUDITORY	MOTOR

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VISUAL	AUDITORY	MOTOR
•A social story on hugging/appropriate touch.		
• Demonstrating appropriate touch (both the type of touch as well as where to touch) for different people.		
• Have a picture of people they can hug and/or pictures of "Strangers" with an X through them.		
• Circles Curriculum.		



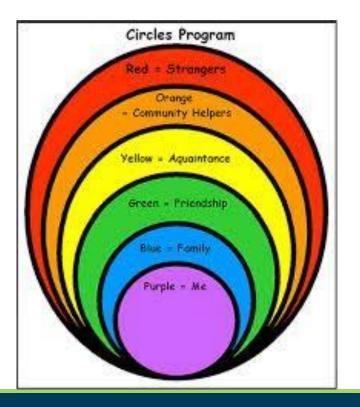
VISUAL	AUDITORY	MOTOR
•A social story on hugging/appropriate touch.	 Verbal praise when they touch appropriately ("good job"). 	
• Demonstrating appropriate touch (both the type of touch as well as where to touch) for different people.	 Verbal prompts when they touch inappropriately ("quiet hands").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



VISUAL	AUDITORY	MOTOR
•A social story on hugging/appropriate touch.	•Verbal praise when they touch appropriately ("good job").	 Practicing appropriate touch. Different types Different 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.Have a picture of people they can	 Listen to/read a social story about hugging. 	 Role play. Write a list of people they can hug.
hug and/or pictures of "Strangers" with an X through them.	• Circles Curriculum.	• Circles Curriculum.
Circles Curriculum.		

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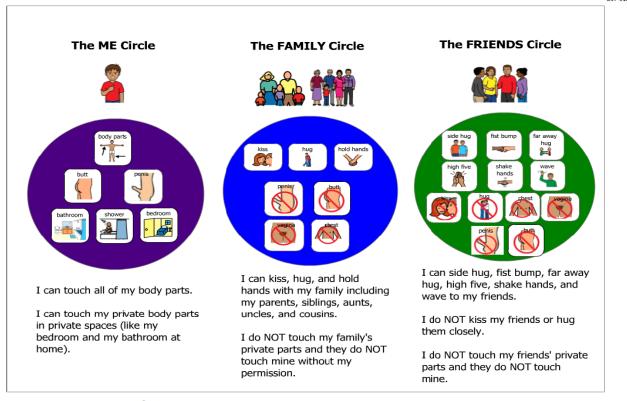
Circles curriculum[©]



Published by Stanfield Publishing and created by Leslie Walker-Hirsch



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Adapted from the Circles Curriculum ®



Appropriate Touch for People in My Life



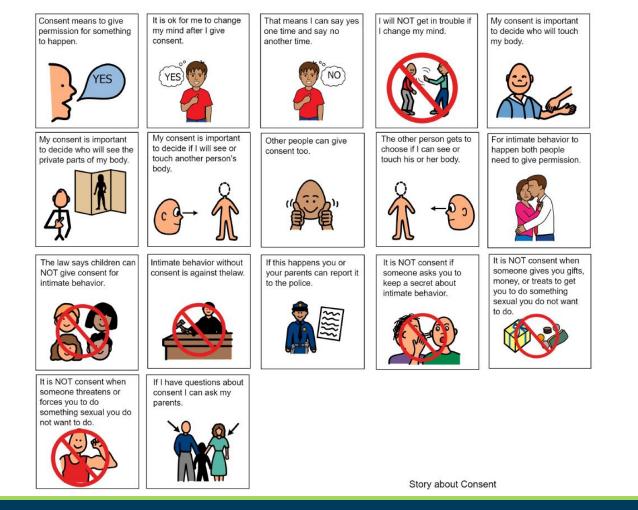
Sample video on appropriate touch

Appropriate Touch



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.

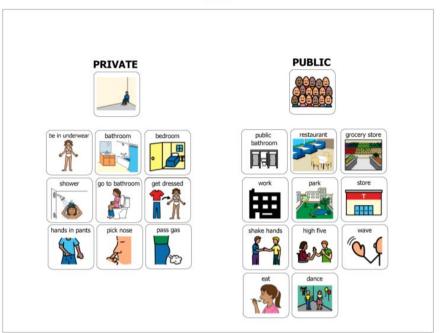




Public and private

PRIVATE VS. PUBLIC

FEMALE



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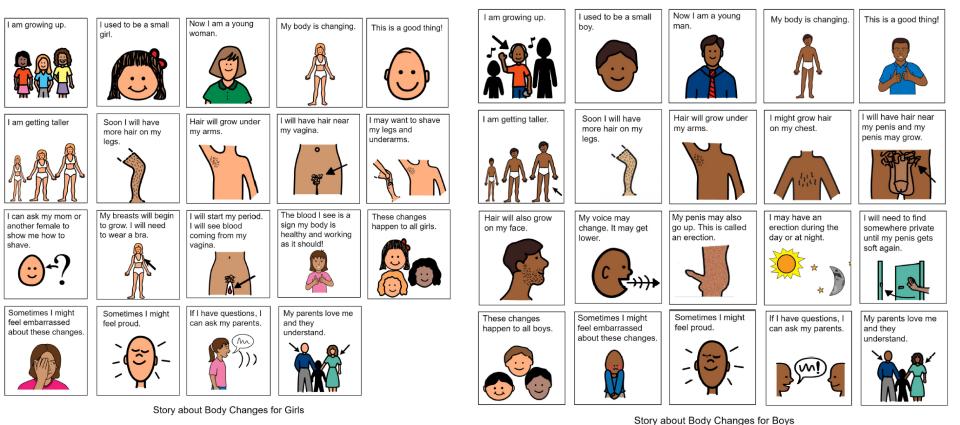
Public and private



Story about Public

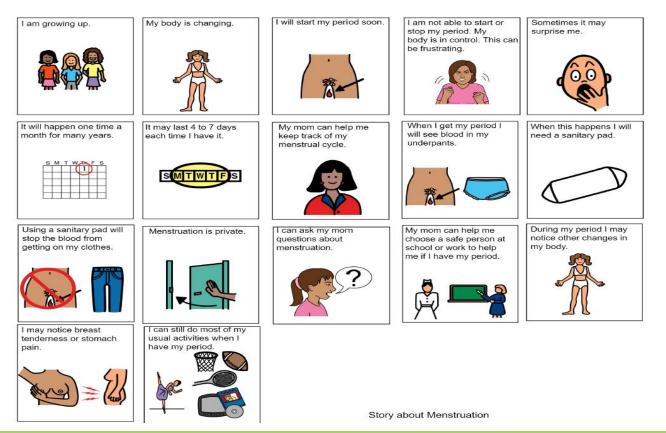
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Body changes



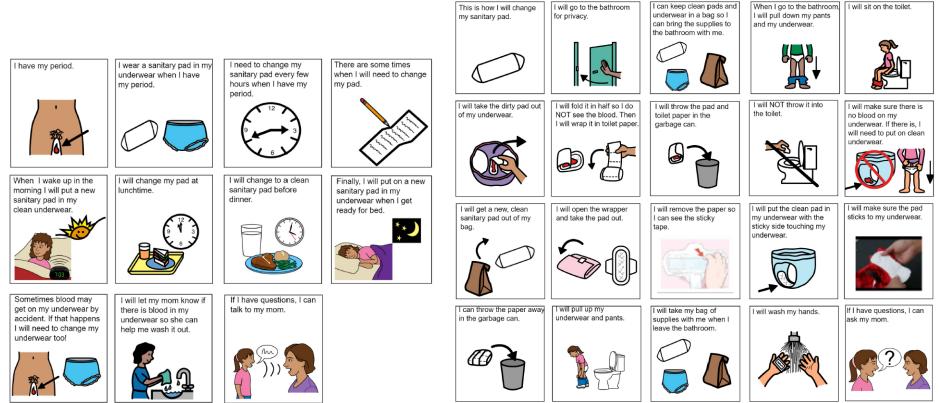
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Menstruation





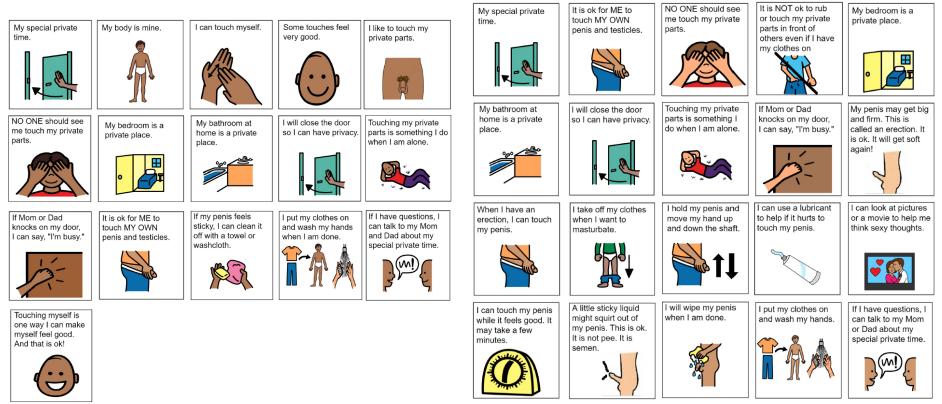
Menstruation



A story about changing a sanitary pad- Part 2

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Masturbation



A Story about Male Masturbation

Story about How to Masturbate-Male

Orientation vs. Identity

Sexual orientation

Attraction to other people

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

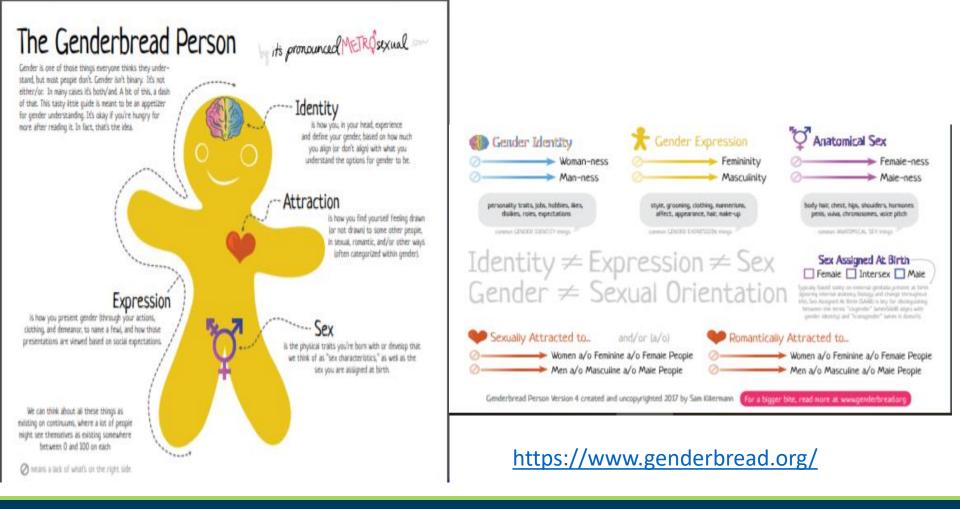
Sexual/Gender identity

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



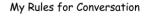
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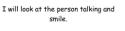
Social skills

Why are conversation skills important in romantic relationships?

They help us communicate!

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





I will listen to what others are saying.

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 <u>;</u> am confused.

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Compromise 1

Do one thing that they both want

Cristina Jacob



What does it mean?

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

Compromise...

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



Jacob

Cristina

WHAT SHOULD JACOB & CRISTINA DO?

Compromise 2

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









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

Compromise 3



Jacob AND Cristina

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to do.















Time 1











Social skills

Sharing touch and affection

Types of touch and affection

Hugging

Holding hands

Kissing

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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

What is rejection?

- · You do not get something that you want
- Someone tells you "No"

Examples of rejection:

You do not get the job

you want





Your boyfriend or girlfriend breaks up with you

You family tells you you cannot have something





Your friend does not want to hang out

Your crush does not like you back

Is rejection OK?

- 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





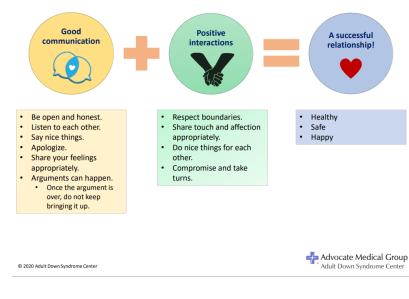
Jacob

Cristina

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

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Ingredients for a successful relationship

BREAKING UP



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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!
- Use the concepts of communication, respect, and safety.
- Teach the way the person learns best!
- It is ok to ask for help!

Resources

- Healthy Relationship Workbook by The Arc of Spokane- <u>http://www.arc-</u> <u>spokane.oResrg/Healthy%20Relationship%20Workbook</u> .pdf
- Sexuality across the Lifespan-Florida Developmental Disabilities Council-<u>http://www.fddc.org/sites/default/files/file/publications</u> /Sexuality%20Guide-Parents-English.pdf
- Healthy Relationships Toolkit by Vanderbilt Kennedy Center <u>https://vkc.mc.vanderbilt.edu/healthybodies/</u>

Resources cont.

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

https://www.planetpuberty.org.au/



Resources cont.

TeachABodies dolls

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

• Circles Curriculum

https://stanfield.com/product/circles-curriculumbundle-w1004-38/

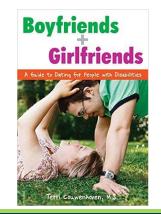
• Life Horizons Curriculum

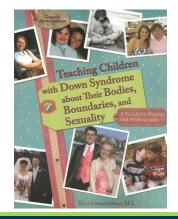
https://stanfield.com/product/life-horizons-family-lifeprogram/



Resources cont.

- Boyfriends and Girlfriends by Terri Couwenhoven
- Teaching Children with Down Syndrome about their Bodies, Boundaries, and Sexuality by Terri Couwenhoven







Videos

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



Online Resource Library

- Contains videos, articles, and booklets on a variety of topics
- Resources are continually being updated.

COVID-19 Resources Review articles, resource lists, and videos related to COVID-19 and Down syndrome. Adult Down Syndrome Center | Resource Library For Families For Health Care For People with & Caregivers Professionals **Down Syndrome** EL Video Related Projects **Events**, Classes News & Programs Gallery Organizations See Our Latest View News Projects Articles View All See Listing of Links See the Schedule

I'm looking for...

Q

MENU =

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Social Skills

All Social Skills

Social Skills for People with DS

Social Skills for Families and Caregivers

Puberty, Sexual Health, and Relationships

All Puberty, Sexual Health, and Relationships

Puberty, Sexual Health, and Relationships for People with DS

Puberty, Sexual Health, and Relationships for Families and Caregivers

MENU

Q

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

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Adult Down Syndrome Center | Resource Library



Facebook

Adult Down Syndrome Center

We are excited to share the recent publication of our study on the prevalence of endocrine disorders in individuals with Down syndrome. The Adult Down Syndrome Center collaborated with the Advocate Aurora Research Institute and University of Chicago. Individuals with Down syndrome were more likely to have thyroid disorders. type 1 diabetes, and gout and less likely to have thyroid disorders. type 1 diabetes, and sex-matched counterparts. The findings highlight the need for health...See more

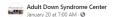


Adult Down Syndrome Center January 25 at 7:00 AM · @

Fear of heights is a common fear identified by individuals with Down syndrome and their families who come to our clinic. The providers at the Adult Down syndrome Center have observed that many people with Down syndrome seem to have a difference in depth perception which may contribute to this fear. In the article linked below, Dr. Brian Chicoine shares more on this topic, including ways to support a person with Down syndrome who may have a fear of heights.

https://adscresou... See more





Visuals can assist people with and without Down syndrome in many ways. We do not think that they are something that we "outgrow." In fact many of us use visual supports (such as apps on our phones todo lists, calendars, etc.) on a daily basis! They can be used to set and manage expectations, establish routines, communicate, learn new skills, and more. Our occupational therapist Dr. Katie Frank shares information about the use of visual supports in the article from our Reso... See more



Visual Supports for Adolescents & Adults with Down Syndrome

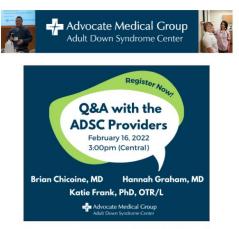
Katie Frank, PhD, OTR/L



https://www.facebook.com/adultdownsyndromecenter

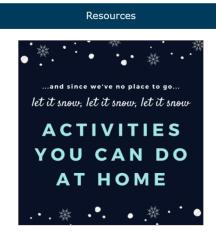


Email list



Do you have questions about health and wellness of adolescents and adults with Down syndrome? Our next webinar is for you! Join Brian Chicoine, MD, Katie Frank, PhD, OTR/L, and Hannah Graham, MD for a Q&A on Wednesday, February 16, at 3:00pm (Central). Questions may be submitted before the webinar and/or during the webinar. Please click the button below to register and submit a question.





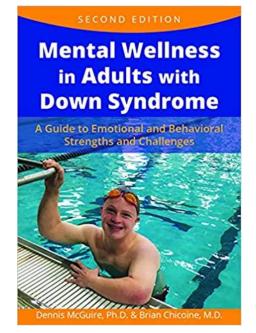
Even if the weather outside is frightful, there are many activities we can do at home to fight boredom, stay active, be social, and have fun. We recently updated our "Activities You Can Do at Home" resource. There are ideas for arts and crafts, cooking, education and learning, fitness and physical activity, games, and more.



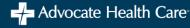
http://eepurl.com/c7uV1v



Free Copy of the Mental Wellness book



https://adscresources. advocatehealth.com/ mental-wellness-inadults-with-downsyndrome-2ndedition/



Contact information

Katie Frank, PhD, OTR/L Katherine.frank@aah.org 847-318-2303

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