Supporting Healthy Sexuality for Individuals with Down Syndrome
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, community-based 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 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).
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
Sexuality defined

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

**Physical:**
- body parts; sex; intimacy and sexual experiences

**Emotional:**
- body image and self-esteem; sexual thoughts, fantasies, and ideas; attitudes and beliefs; relationships

**Identity:**
- gender and gender roles; orientation
Sexuality topics to consider

- Human development
- Dating and relationships
- Sexual activity
- Sexual health
- Pregnancy
- Rights and responsibilities
Sexuality topics to consider

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

- 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
Sexuality topics to consider

- Kissing
- Touching
- Foreplay
- Intercourse
- Safety
- Consent
Sexuality topics to consider

- Use of contraception
- Sexually transmitted infections (STIs)
- Menstruation
- Masturbation
- Wet dreams
- Erections
- Sexual health exams
Sexuality topics to consider

- How it happens
- Body changes
- Giving birth
- Raising a child
Sexuality topics to consider

- Laws and consequences
- Consent
- Exploitation and abuse
- Responsibilities of marriage
- Responsibilities of parenting
## Specific topics for healthy relationships

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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.
# Learning strategies

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Circles curriculum©

Published by Stanfield Publishing and created by Leslie Walker-Hirsch
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.

Adapted from the Circles Curriculum®
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.
Consent means to give permission for something to happen.

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

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

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

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

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

Other people can give consent too.

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

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

The law says children can NOT give consent for intimate behavior.

Intimate behavior without consent is against the law.

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

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

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.

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

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

Story about Consent
Public and private
### Public and Private

**Privacy means no one should see my body without my permission.**

- My body is private.
- My body parts that can be covered by a bathing suit are private.
- My penis, scrotum, and bottom are private body parts.
- My parents can see my private body parts with my permission.

**Public means lots of other people are around.**

- School is a public place.
- My classroom at school is a public place.
- Work is a public place.
- The bathroom at school or work is a public place.

**My doctor can see my private parts during a medical exam with my permission.**

- No one else should see my private parts without my permission.
- Some behaviors are private.
- No one can enter my space without my permission.
- Getting dressed is a private behavior.

**I can change clothes at school or work in a bathroom stall because it is private. The door closes and locks.**

- The bathroom stall at school or work is a private space.
- I can use the toilet in a bathroom stall because it is private. The door closes and locks.

**Some places are private.**

- My bathroom at home is private.
- The bathroom at school or work is not private. It is public.
- My bedroom is a private place.

**I can do lots of things in public!**

- I can eat in public.
- I can play with my toys and my friends in public.
- I can talk to my parents and friends in public.

**When I went privacy in my room, I can close the door.**

- When I am in public I should NOT show the private parts of my body.
- When I am in public I should NOT show private behaviors.
- When I am in public I should NOT talk about private things.

**There are things I can NOT do in public.**

- I can talk to my parents about private and public. I can talk to my parents.
### Story about Body Changes for Girls

- **I am growing up.**
- **I used to be a small girl.**
- **Now I am a young woman.**
- **My body is changing.**
- **This is a good thing!**
- **I will have hair near my vagina.**
- **I may want to shave my legs and underarms.**
- **I will have hair near my vagina.**
- **I will start my period.**
- **I will see blood coming from my vagina.**
- **The blood I see is a sign my body is healthy and working as it should!**
- **These changes happen to all girls.**
- **Sometimes I might feel embarrassed about these changes.**
- **Sometimes I might feel proud.**
- **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.**
- **Sometimes I might feel proud.**
- **If I have questions, I can ask my parents.**
- **My parents love me and they understand.**

### Story about Body Changes for Boys

- **I am growing up.**
- **I used to be a small boy.**
- **Now I am a young man.**
- **My body is changing.**
- **This is a good thing!**
- **I will have more hair on my legs.**
- **Hair will grow under my arms.**
- **I am getting taller.**
- **Soon I will have more hair on my legs.**
- **Hair will grow under my arms.**
- **I might grow hair on my chest.**
- **I will have hair near my penis and my penis may grow.**
- **I will need to find somewhere private until my penis gets soft again.**
- **I may have an erection during the day or at night.**
- **My penis may also go up. This is called an erection.**
- **These changes happen to all boys.**
- **Sometimes I might feel embarrassed about these changes.**
- **Sometimes I might feel proud.**
- **If I have questions, I can ask my parents.**
Menstruation

I am growing up.

My body is changing.

I will start my period soon.

I am not able to start or stop my period. My body is in control. This can be frustrating.

Sometimes it may surprise me.

It will happen one time a month for many years.

It may last 4 to 7 days each time I have it.

My mom can help me keep track of my menstrual cycle.

When I get my period I will see blood in my underpants.

When this happens I will need a sanitary pad.

Using a sanitary pad will stop the blood from getting on my clothes.

Menstruation is private.

I can ask my mom questions about menstruation.

My mom can help me choose a safe person at school or work to help me if I have my period.

During my period I may notice other changes in my body.

I may notice breast tenderness or stomach pain.

I can still do most of my usual activities when I have my period.

Story about Menstruation
Menstruation

I have my period.

I wear a sanitary pad in my underwear when I have my period.

I need to change my sanitary pad every few hours when I have my period.

There are some times when I will need to change my pad.

When I wake up in the morning I will put a new sanitary pad in my clean underwear.

I will change my pad at lunchtime.

I will change to a clean sanitary pad before dinner.

Finally, I will put on a new sanitary pad in my underwear when I get ready for bed.

Sometimes blood may get on my underwear by accident. If that happens I will need to change my underwear too!

I will let my mom know if there is blood in my underwear so she can help me wash it out.

If I have questions, I can talk to my mom.

This is how I will change my sanitary pad.

I will go to the bathroom for privacy.

I can keep clean pads and underwear in a bag so I can bring the supplies to the bathroom with me.

When I go to the bathroom, I will pull down my pants and my underwear.

I will sit on the toilet.

I will take the dirty pad out of my underwear.

I will fold it in half so I do NOT see the blood. Then I will wrap it in toilet paper.

I will throw the pad and toilet paper in the garbage can.

I will NOT throw it into the toilet.

I will make sure there is no blood on my underwear. If there is, I will need to put on clean underwear.

I will get a new, clean sanitary pad out of my bag.

I will open the wrapper and take the pad out.

I will remove the paper so I can see the sticky tape.

I will put the clean pad in my underwear with the sticky side touching my underwear.

I will make sure the pad sticks to my underwear.

I can throw the paper away in the garbage can.

I will put up my underwear and pants.

I will take my bag of supplies with me when I leave the bathroom.

I will wash my hands.

If I have questions, I can ask my mom.

A story about changing a sanitary pad - Part 2
Masturbation

My special private time.
My body is mine.
I can touch myself.
Some touches feel very good.
I like to touch my private parts.

My special private time.
It is ok for ME to touch MY OWN penis and testicles.
I will close the door so I can have privacy.
Touching my private parts is something I do when I am alone.

My bedroom at home is a private place.
I will close the door so I can have privacy.
Touching my private parts is something I do when I am alone.

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

NO ONE should see me touch my private parts.

If Mom or Dad knocks on my door, I can say, "I'm busy."
If my penis feels sticky, I can clean it off with a towel or washcloth.
If I have questions, I can talk to my Mom and Dad about my special private time.

When I have an erection, I can touch my penis.
I take off my clothes when I want to masturbate.
I hold my penis and move my hand up and down the shaft.
I can use a lubricant to help if it hurts to touch my penis.

I put my clothes on and wash my hands.

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

A little sticky liquid might squirt out of my penis. This is ok. It is not pee. It is semen.
I will wipe my penis when I am done.
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.

A Story about Male Masturbation

Story about How to Masturbate-Male

Advocate Aurora Health
## 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
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.

My Rules for Conversation
- I will look at the person talking and smile.
- 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 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 1
Do one thing that they both want to do.
- Jacob
- Cristina

Compromise 2
Do one of their choices this time and the other person’s choice the other time.
- Time 1
- Time 2
- Jacob
- Cristina

Compromise 3
Decide together to do something that is not either of their first choices.
- Jacob AND Cristina
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.

HANDLING REJECTION

What is rejection?
- You do not get something that you want
- Someone tells you “No”

Examples of rejection:

- Your boyfriend or girlfriend breaks up with you
- You do not get the job you want
- 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:

- It is OK to be sad
- Take some deep breaths
- Use an “I” statement
- Talk to friends or family
- Remember that it will get better

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Adult Down Syndrome Center
Social skills

How to Plan a Date

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

How to Plan a Date

Ingredients for a successful relationship

- Good communication
  - Be open and honest.
  - Listen to each other.
  - Say nice things.
  - Apologize.
  - Share your feelings appropriately.
  - Arguments can happen.
    - Once the argument is over, do not keep bringing it up.

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

= A successful relationship!

What is breaking up?
Ending your relationship with your boyfriend or girlfriend

People break up when...
- They do not want to spend time together anymore
- 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
- It is OK to be sad
- Write your feelings
- Talk to friends
- Do your hobbies
- Remember that it will get better
- Stick to your decision

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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- [http://www.arc-spokane.oResrg/Healthy%20Relationship%20Workbook.pdf](http://www.arc-spokane.oResrg/Healthy%20Relationship%20Workbook.pdf)


• **Healthy Relationships Toolkit** by Vanderbilt Kennedy Center [https://vkc.mc.vanderbilt.edu/healthybodies/](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/personal/famplan/educators/SpecialEducation.aspx](http://www.kingcounty.gov/healthservices/health/personal/famplan/educators/SpecialEducation.aspx)

- **Sexuality and Disability: A Guide for Parents** by Alberta Health Services

- **Planet Puberty**
Resources cont.

- **TeachABodies dolls**
  https://teach-a-bodies.com/

- **Circles Curriculum**

- **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
Videos

- **Amaze.org**
  - AMAZE Org – YouTube

- **National Council on Independent Living**
  - Sex Ed for People With I/DD. – YouTube
Online Resource Library

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

[adscresources.advocatehealth.com](http://adscresources.advocatehealth.com)
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
Facebook

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.

REGISTER NOW

http://eepurl.com/c7uV1v

Resources

...and since we’ve no place to go...
let it snow, let it snow, let it snow

ACTIVITIES YOU CAN DO AT HOME

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.

Explore activities
Free Copy of the Mental Wellness book

Contact information

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Advocate Medical Group Adult Down Syndrome Center
https://adscresources.advocatehealth.com/