



REAL CONVERSATIONS ON PARENTING AND DISABILITY

**PUBERTY, SEXUALITY, AND BEHAVIOR:
HOW TO GUIDE YOUNG PEOPLE
WITH DISABILITIES**

RESOURCES ON SEXUALITY & SEX EDUCATION FOR INDIVIDUALS WITH DISABILITIES (AND THEIR PARENTS/CAREGIVERS)

Books

- Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals by Terri Couwenhoven (2007)
- Boyfriends and Girlfriends: A Guide to Dating for People with Disabilities by Terri Couwenhoven (2015) - Written at a 3rd grade reading level. Great to read together!
- Sexuality: Your Sons and Daughters with Intellectual Disabilities by Melberg Schwier and Dave Hingsburger (2000)
- Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel (2003)
- Sexuality and Relationship Education for Children and Adolescents with Autism-Spectrum Disorders: A Professional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Responding to Inappropriate Behaviors by Davida Hartmann (2014)

Online Resources

- Center for Parent Information & Resources, Sexuality Education for Students with Disabilities: <http://www.parentcenterhub.org/sexed/>
- RespectAbility - Sexual Education Resources: <http://bit.ly/2K9HPUb>
- Autism Speaks - Sexuality Education for Children and Adolescents with Developmental Disabilities: An Instructional Manual for Parents or Caregivers of and Individuals with Developmental Disabilities (Florida Developmental Disabilities Council, Inc.): <http://bit.ly/2wAG00H>
- Planned Parenthood - Information and resources for parents: <http://bit.ly/2wqvb10>
- Kids Health: www.kidshealth.org
- Inner Learning Online: www.innerbody.com
- SexEd Library by the Sexuality Education and Information Council of the United States (SIECUS): www.sexedlibrary.org

Puberty, Behavior & Sexuality

Tips & Techniques for Support



Values Exercise



**CORE
VALUES**

Fact or Fiction?

People with disabilities do not feel the desire to have sex (if disabled in one way disabled in every way)

People with developmental and physical disabilities are asexual, childlike, sexually innocent (do not possess maturity to learn about sexuality)

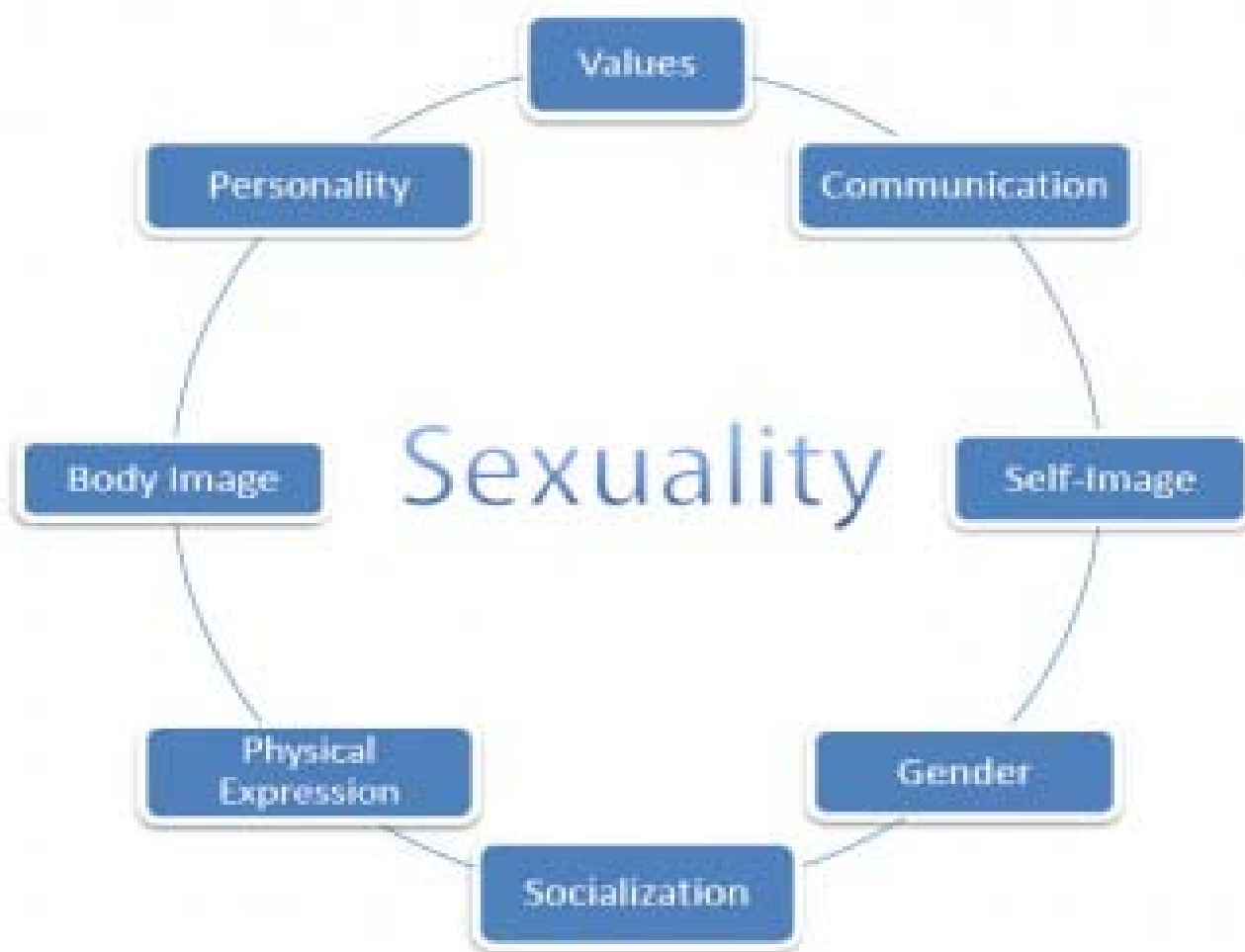
People with disabilities are sexually impulsive (oversexed and unable to control their sexual urges) men aggressive & women promiscuous

People with disabilities will not marry or have children so they have no need to learn about sexuality

Sex...shhh

- How much detail must I tell her? Won't she just get confused?
- Is it really necessary to broach the subject of intercourse since Johnnie is simply not capable of a close relationship, let alone a sexual encounter. Besides, he'll be accompanied all his life by a support worker, so what chance is there that he will have sex?
- Ronda is non verbal—how can I possibly teach her information related to relationships, and what is the chance that she would even understand it?
- Joey has a severe developmental disability and will be child-like for the rest of his life. He won't need that type of information.
- Bobbie is still young, there is a lot of time to think about teaching him this type of information in five years or even later. What has "sex" or "sexuality" got to do with him now?

What is Sexuality?



- Social phenomenon (**sociological**)
 - Friendship
 - Warmth
 - Approval
 - Affection
 - Social outlets
 - Spiritual
 - Hygiene
 - dress
- What we feel about ourselves (**psychological**)
 - Whether we like ourselves
 - Our understanding of ourselves as men and women (gender identification)
 - What we feel we have to share with others
- Having a physical sexual relationship (**biological/physical**)
 - Physical sensations or drives our bodies experience
 - Genital activity is one small part of human sexuality

Harmful Effects of Repression of Sexual Expression

- Emotional instability
- Sex related physical problems
- Anger
- Frustration and confusion
- Heightened anxiety
- Verbal/physical aggression
- Physical discomfort
- Social-sexual misconduct
- Mental health problems
- Develop poor self esteem
- Poor decision making
- Feelings of loneliness
- Isolation
- At-Risk behavior
- Criminal behavior
- Lack of impulse control
- Inferiority complex (being told they are bad/evil)
- Depression

Adolescent Brain Development

ID/DD

Puberty dev't the same

Mood swings
Social-sexual changes

BIOLOGICAL

EMOTIONAL/SOCIAL

DIFFERENCE IS IN COGNITION

More challenging to express feelings
Need more concrete language

WITHOUT ID/DD

Puberty dev't the same

Mood swings
Social-sexual changes

More variety of ways to express feelings
May understand more complex language

Puberty: Physical Development

■ FEMALE

8-11yrs- Usually begins...

11-12yrs- Breast Growth, Height and Weight Gain.

12-13yrs- Breast Growth cont., Vagina is Enlarging, Produces Discharge as a Cleansing Process.

13-14yrs- Pubic Hair Growth.

15yrs- Final Stages of Dev't, Menstrual Period and Ovulation Have Usually Begun.

■ MALE

9-12 yrs- Usually begins...

12-13yrs- Testicles & Scrotum Begin Enlarging.

13-14yrs- Penis Begins to Grow in Length, Hair, Height, and Voice Changes.

14-15yrs- Dev't continues...

16 yrs- Nearing Adult Appearance

Puberty: Social & Emotional Development.

- During adolescence, you'll notice changes in the way your child interacts with family, friends and peers.
- Every child's social and emotional development is different.
- Your child's development is shaped by your child's unique combination of genes, brain development, environment, experiences with family and friends, and community and culture.

Puberty: Social & Emotional Development

- Social changes and emotional changes show that your child is forming an independent identity and learning to be an adult.



- Remember that the rate of social and emotional development varies widely, both for typically developing children and children with a disability.

Puberty: Social and Emotional Development

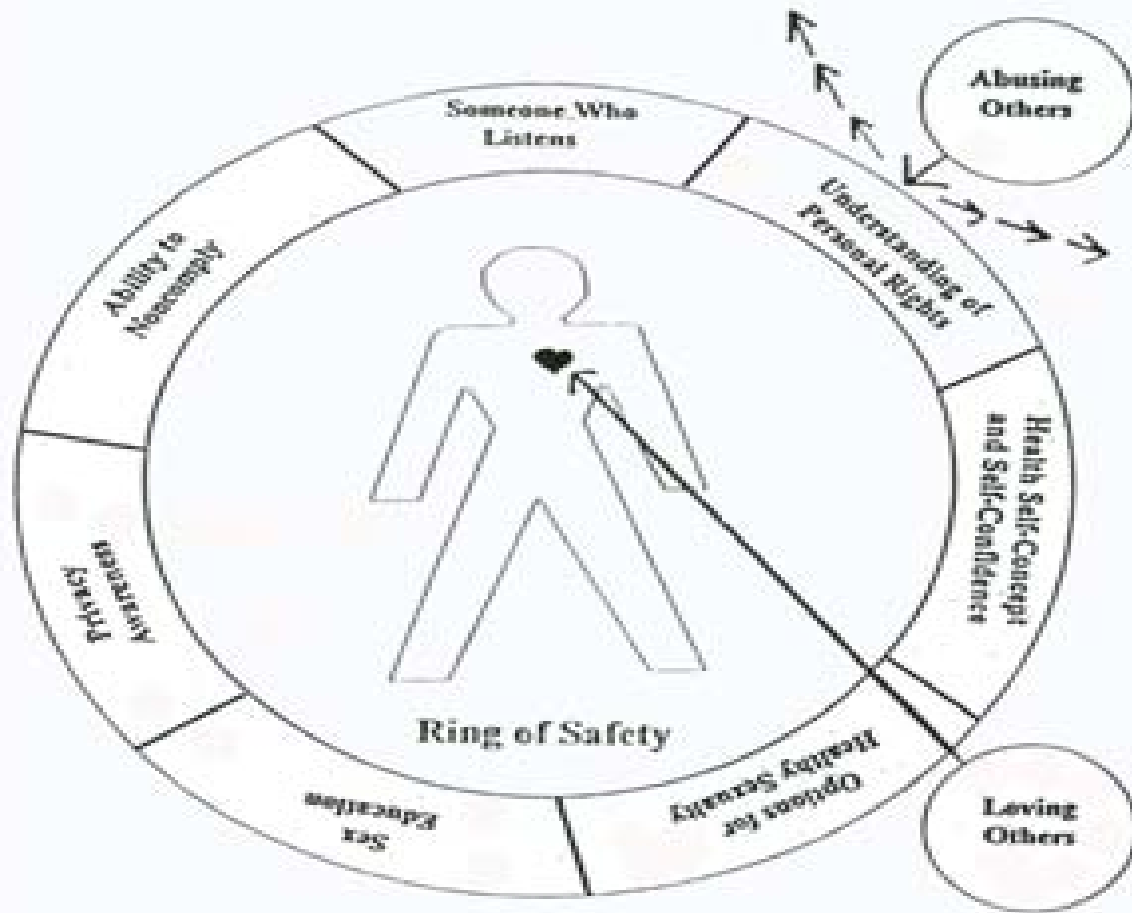
- Have difficulties monitoring and expressing emotions
- Difficulties with peer and social relationships
- Might have difficulties making and keeping friends
- Moodiness, has more arguments with you
- Sees things differently from you
- Antisocial behavior and risk-taking behavior
- Difficulties balancing emotions and behavior
- Wants to spend less time with family

So What May I See?



- **Sees things differently from you**
- **Antisocial behavior and risk-taking behavior**
- **Difficulties balancing emotions and behavior**
- **Wants to spend less time with family**
- Might have difficulties monitoring and expressing emotions
- Difficulties with peer and social relationships
- Might have difficulties making and keeping friends
- Moodiness, has more arguments with you

THE RING OF SAFETY



Where do I start?

- What do I know?
 - What do I still need to know?
 - Where can I find information?
 - Who else can help me?
-
- What information does my child already have?
 - What information does my child need?
 - How quickly is the information needed?

Where Do You Want Your Child to Learn About Sexuality?

- Peers
- Media
- School
- Parents
- Internet

Why Social-Sexual Education?

- Decreases the Likelihood of Abuse.
- Combats Myths & Misinformation.
- Promotes Social Skills, Personhood, Pleasure.
- Reduces Fear, Anxiety, Worry.
- Increases Self-Awareness, Gender Comfort.
- Allows for Maturity, and Healthy Relationships.

Mild IDD

- Similar to average or normative psychosocial-sexual behavior in society.
- Explores, adapts, and controls sexual impulses and urges in similar ways as majority of society.
- Responds to verbal mode of sex education/sex counseling/sex therapy.
- Capable of developing appropriate adaptive skills with current sex education/counseling/therapy methods

Moderate IDD

- Secondary sexual characteristics may be delayed.
- Functions more on a primary reward and basic reinforcement system level.
- May respond to verbal mode of sex education/counseling to develop more appropriate adaptive behavior; however, may require techniques of behavior modification systems to be effective.

Severe/Profound IDD

- Very poor control of sexual impulses.
- Lack of development of adaptive psychosocial-sexual behavior.
- Problems comprehending societal rules, especially private vs public, and developing adaptive behaviors in these areas.
- The technique of behavior modification may be **most** effective in affecting change in this group
- Functions primarily by having basic needs met.
- Predominant reactions are impulsive.
- Limited ability to predict or foresee consequences of sensual/sexual behavior.
- Pleasure seeking frequently in self-stimulating.
- Often masturbates excessively or in a harmful way unknowingly.

CHALLENGES

- People with disabilities may have:
 - Difficulty learning
 - Limited genital and other tactile sensations
 - Communication problems
 - Uncertainty about their sexual function and fertility status
- Issues that may hinder development of healthy body image and self-concept include:
 - Use of braces, crutches, wheelchair
 - Bladder and bowel management routines
 - Physical differences from peers (atrophy)
 - Diminished gender role expectations from society
 - Mistrust of own body



Socialization

- Children with disabilities have:
 - -Fewer opportunities than their peers to observe, develop and engage in appropriate social and sexual behavior
 - -Fewer opportunities to acquire information from peers
 - -Often held back by social isolation as well as functional limitations .
 - **By fostering development of social skills, parents and educators can provide opportunities to learn about the social contexts of sexuality and the responsibilities of exploring and experiencing ones own sexuality.**

Socialization

- National Dissemination Center for Children with Disabilities (NICHCY) recommends:
 - Helping children develop hobbies and pursue interests or recreational activities in the community and after school
 - Children with disabilities should engage in social opportunities and to grow and learn from social errors
 - Extra-curricular activities present opportunities for friendship based on commonality of interests and provide opportunities to develop competence and self-esteem

Why “Behaviors”?

- Inappropriate sexual behavior by individuals with disabilities can stem from:
 - Lack of opportunity for appropriate sexual expression
 - Ignorance of what is considered appropriate behavior
 - Poor social education
- Behavior that leads teens with disabilities into trouble as perpetrators may not necessarily be atypical for adolescents but it also involves either bad judgment on the part of the person with a disability or a hasty reaction on part of parents, school, employer.
- Opportunities for privacy are less frequent for people with special needs
- Comprehensive sexuality education often withheld from this population
- Not surprising that teens with disabilities display sexuality inappropriately
- Whether sexual behavior is considered appropriate depends on the location in which the behavior takes place – need to look at problematic behavior in its context

Issues

- Problems most frequently mentioned by parents regarding sexuality education are:
 - Inability to answer questions
 - Uncertain of what children know or should know
 - Confusion, anxiety and ambivalent attitudes toward sexuality of their children
 - Equate learning with intentions to perform sexual activities

Parents as Sex Educators

- Parents of children with developmental disabilities tend to be uncertain about the appropriate management of their child's sexual development
- Concerned about
 - Overt signs of sexuality
 - Physical development during puberty
 - Genital hygiene
 - Fears of unwanted pregnancy
 - STI's
 - Embarrassing or hurtful situations
 - Fear that their child will be unable to express sexual impulses appropriately
 - Targets of sexual abuse or exploitation

Parents are the First Sex Educators

- Parents need to help their child develop life skills
- Without appropriate social skills young people may have difficulty making and keeping friends and may feel lonely and different.
- Without important sexual health knowledge, young people may make unwise decisions and or take sexual health risks.

Self-touch

- Sexual self-stimulation or masturbation is normal, natural and non-harmful behavior throughout the life cycle
- Self-stimulation can be a way of learning to be more comfortable with and/or enjoying one's sexuality by getting to know one's body
- Self-stimulation is a private behavior and inappropriate in public places

Public vs. Private

- People with disabilities are capable of learning how to act appropriately in public and private places
 - Many inappropriate actions and activities reflect confusion, lack of awareness and limited judgment
- Many social problems indicate a limited understanding about public and private places, private parts of the anatomy and public and private behaviors.
 - Discouraged from public engaging in activities such as:
 - Exposing private parts of the anatomy by undressing, pulling down or lifting up clothing
 - Scratching or touching genitals
 - Fixing or adjusting underclothing
 - Self-stimulation

General Guidelines for Parents

- Be clear when discussing relationships (mother father vs, Paul and Carol)
- Use teachable moments that arise in daily life (e.g., friends pregnancy, marriage, adoption)
- Be honest when children ask you questions
- Always acknowledge and value your child's feelings and experience.
- Be willing to repeat information over time – don't expect your child to remember everything you said

General Guidelines for Parents

- Be able to talk about and ask questions about sexuality related issues
- Prepare for puberty (parent & pre-adolescent)
 - Male vs. female body parts (correct names, changes)
 - Menstruation
 - Care of genitals & general body care
- Use pictures in communication/teaching
- Seek out/ask for support

General Guidelines for Parents

- Be ready to assert your personal privacy boundaries
- Use accurate language for body parts and bodily functions.
 - Children with accurate language are more likely to report abuse if it occurs

It's Not Just About Sex!

- Social Concepts (Friendships, Social Skills) are as Important as Sexual Concepts (Masturbation, Pregnancy Prevention).
- Be Proactive, Not Reactive: Teach the Concepts **Before** the Issue Presents Itself!
- Stay Neutral; Avoid Judgment.
- Model Appropriate Boundaries by choosing Private Locations to Discuss Topics and/or Issues.
- Use Repetition, Especially with Key Concepts.
- Teach Complex Tasks in Simpler, Individual Steps, and In Chronological Order.

So... What to Teach?

- Private vs. Public
- Boundaries
- Good touch/bad touch
- Hidden Social Etiquette
- Teach concretely, especially abstract concepts.
- Time and Place
- Social-Sexual Education (curriculum)

What to Teach?

- Body Image
- Self-Esteem
- Being Healthy
- Hygiene
- Puberty
- Social Skills
- Private vs. Public
- Sexual Orientation
- Menstruation
- Abuse Prevention
- Masturbation
- Relationships & Boundaries
- STDs, Birth Control, Pregnancy

Parents as the first Social Sexual Educators

- Normalize the Discussion of Sexuality!
- Use concrete language at their cognitive level & pictures.
- Making it Taboo Encourages Secrecy and Increases Vulnerability.
- You may need to initiate the conversation!
- Be honest and give correct information.
- Respond to All Sexual Issues Non-Judgmentally.
- If Necessary, Refer Loved Ones for Additional Services related to Sexuality, such as Sexuality Training, Psychotherapy, or Consent Determination.

My Body Safety Rules

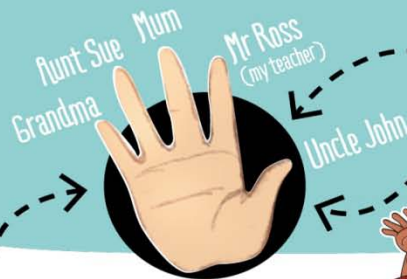
My body is my body and it belongs to me!

I can say, 'No!' if I don't want to kiss or hug someone.
I can give them a high five, shake their hand or blow them a kiss.
I am the boss of my body and what I say goes!



I have a Safety Network

These are five adults I trust. I can tell these people anything and they will believe me.
If I feel worried, scared or unsure, I can tell someone on my Safety Network how I am feeling and why I feel this way.



Early Warning Signs

If I feel frightened or unsafe I may sweat a lot, get a sick tummy, become shaky and my heart might beat really fast.

These feelings are called my Early Warning Signs. If I feel this way about anything, I must tell an adult on my Safety Network straightaway.



Secrets

I should never keep secrets that make me feel bad or uncomfortable. If someone asks me to keep a secret that makes me feel bad or unsafe, I must tell an adult on my Safety Network straightaway!

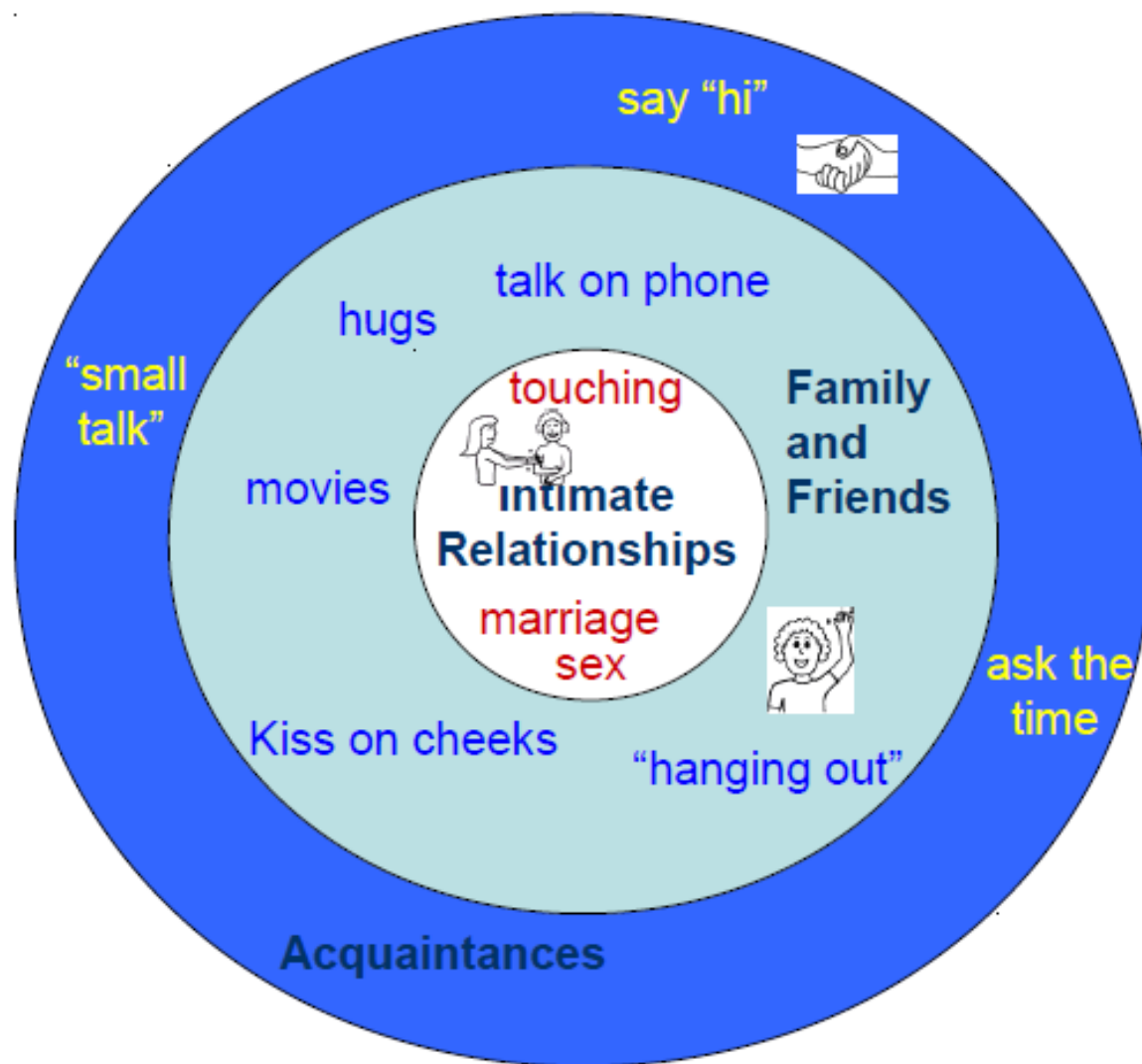


Private Parts

My private parts are the parts of my body under my bathing suit. I always call my private parts by their correct names.
No-one can touch my private parts.
No-one can ask me to touch their private parts. And no-one should show me pictures of private parts. If any of these things happen, I must tell a trusted adult on my Safety Network straightaway.



Circle of Friends



Listening

1

Stop
what you are doing.



2

Look
at the person
who is talking.



3

Be quiet
while the person
is talking.



4

**Ask
questions**
or make comments on
what the person said.



FLIRTING OR SEXUAL HARASSMENT

Flirting

- Is WANTED.
- Feels good; confident feeling.
- Is complimentary.
- Is mutual or shared.
- Is non-threatening.
- Builds the esteem of both people.
- Feels equal to both people

Sexual Harassment

- Is UNWANTED.
- Feels bad; degrading.
- Is one-sided.
- Is threatening.
- Builds up the ego of the giver while tearing down the esteem of the recipient.
- Give one person power over another.
- Is demanding and insulting.

The Five Ways To Describe A Friend

If you are wondering if someone is a friend or not? Check off each one that applies below

Friends are people you have met in person. Friends

Like to do things with each other

Can talk about their personal feeling and experiences

Like to help each other

Like the other person for who they are not what they have, and

Have known each other a long time and can trust each other

Social Stories

Public and Private

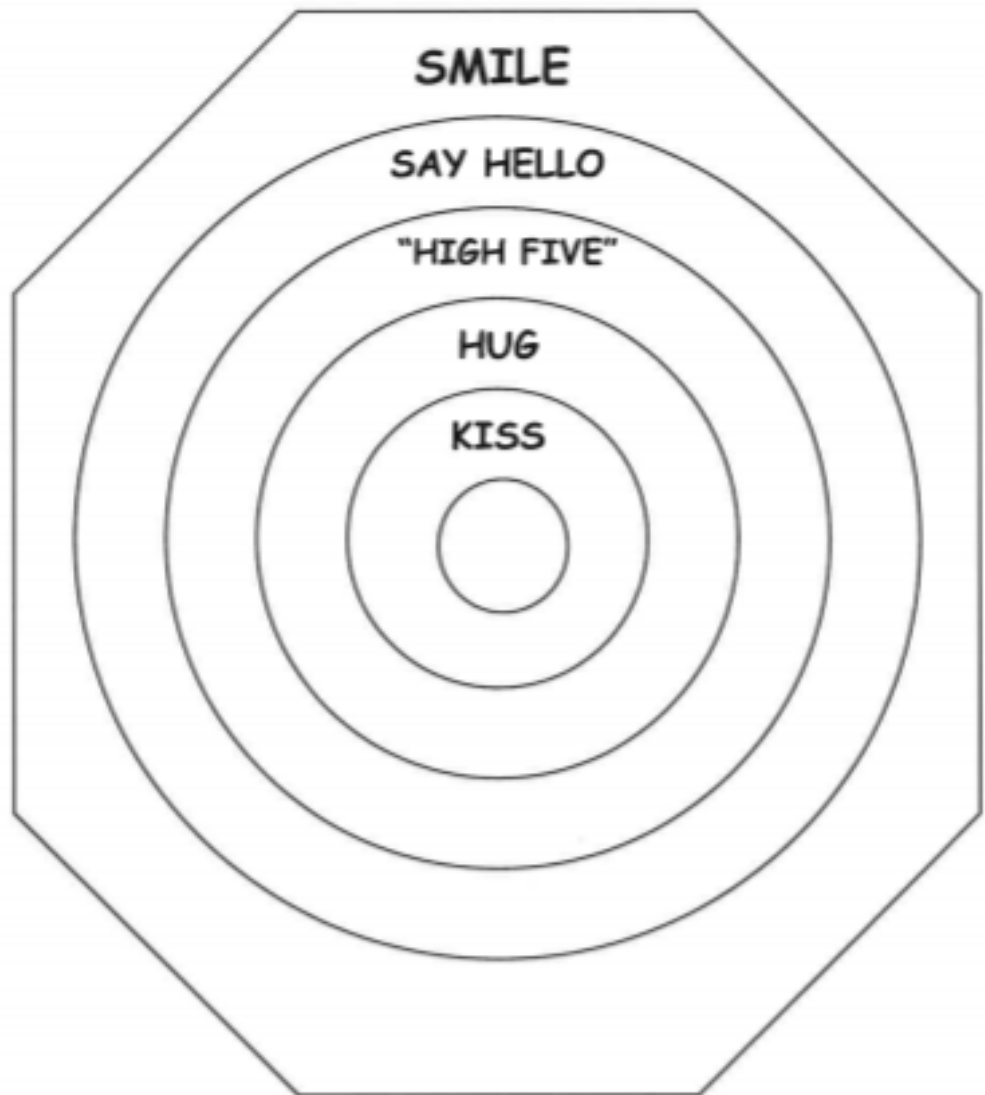
Public places are where other people see and talk with me. I see and talk to people at school, at the store, and at places like McDonalds.

Private places are where I can be alone. When I am in my bedroom or my bathroom at home, this is a private place.

When I want or need to do things like take my clothes off or touch myself in my private areas, I need to be in a private place, like my bedroom at home or my bathroom at home.

In public, like at school or the store, I need to keep my clothes on. This is not the place to touch my own or others' private areas.

I will wait to take my clothes off or to touch myself until I am alone and in a private place.



Adapted from: Pittsburgh Action Against Rape. (July 2000) *Building healthy relationships sexual harassment prevention and relationship skills curriculum kindergarten – 5th grade*. Enola, Pennsylvania: PCAR.

Goals of Sex Education for People with Disabilities

1. To help people with disabilities communicate about sexuality with others without unnecessary guilt or embarrassment in relations to their sexual orientation, their sexual interests and/or activities.
2. To provide accurate sexuality information at cognitively appropriate levels using multi-sensory modes of communication such as pictures, models, role plays, videos, etc.
3. To teach awareness about the body which allows people with disabilities to see themselves to be like others. This generates self-confidence which in turn, will heighten self-esteem.
4. To help make it possible for people with disabilities to enjoy the company of friends by acquiring social skills; and developing positive relationship with others
5. To actively involve the student in the learning process.

Goals of Sex Education for People with Disabilities

6. To help people learn the responsibilities of being a sexual person including customary social patterns.
7. To train people so they will avoid situations where they could be sexually exploited, harmed or abused.
8. To teach people to avoid unsafe or illegal sexual behavior.
9. To help prevent the overprotection that arises from fear of procreation by offering people information about, and help with, birth control.
10. To teach skills that will enable individuals to make responsible choices and deal more effectively with the challenges they may encounter throughout their lives.

**EDUCATION AND TRAINING ARE
THE KEY TO PROMOTING HEALTHY
AND MUTUALLY RESPECTFUL
BEHAVIOR... REGARDLESS OF
DISABILITY.**

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How to Talk to Your Child About Bullying
Video | Resources



Supported Decision Making - Alternative to Guardianship for People with Disabilities
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From School to Work
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How to Get Assistive Technology on Your Child's IEP
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Moving from Early Intervention to Preschool Services
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