

# Sex in the City Is Not Just A Miami Vice

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2:00 – 3:15 PM

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# COMMON MYTHS ABOUT SEXUALITY IN PEOPLE WITH INTELLECTUAL DISABILITY (ID)

They have no interest in sex

Adults with ID are “innocent” and don’t even know what sex is

As a legal guardian, I have the right to make decisions about sexuality, contraception, and reproduction for my adult son or daughter

Adult service agencies restrict sexual activity among housemates, co-workers with ID

People with ID cannot understand and don’t need sex education

# **SPECIAL CONSIDERATIONS RELATED TO FRAGILE X SYNDROME**

Fragile X is an inherited condition

Genetic issues in addition to general concerns about pregnancy  
in females with ID

Potential for multiple family members to be affected by ID,  
increasing possibility of inappropriate sexual interactions  
between siblings, other relatives

# LEGAL ISSUES

Involuntary sterilization: *Buck v Bell* (1927)

Civil Rights Act of 1965

- Protection of marriage and procreation as essential elements of right to privacy

Americans with Disabilities Act (1990)

- Increased protections for people with disabilities

Presumption of Competency

- Individuals are presumed to be competent unless proven otherwise

# LEGAL ISSUES

## Elements of Competency

- Knowledge: able to identify the important aspects of a decision
- Understanding: evidence that the knowledge is comprehended, including moral and physical consequences
- Voluntariness: lack of coercion

# LEGAL ISSUES

## Legal Guardianship

- Assigned by the courts
- Situation-specific (financial, medical)
- Does not cover issues of privacy, including sexual consent, reproductive decision-making, consent for prenatal testing
- Guardian must petition court for specific situation; precedent cases have denied involuntary sterilization

# LEGAL ISSUES

Example: Considerations to be reviewed by the court in the case of involuntary sterilization of an adult daughter with intellectual disability:

- Daughter's chance to become competent in the future?
- Would birth control suffice instead of sterilization?
- Is sterilization in the daughter's best interest? Or is it for the family's/ community's convenience?
- Possibility of trauma/ psychological damage if daughter becomes pregnant v trauma/ damage from sterilization operation?

# LEGAL ISSUES

- Likelihood that daughter will voluntarily engage in sexual activity, or that sexual intercourse will be imposed on her?
- Inability of daughter to understand reproduction/contraception, and likely permanence of this intellectual inability?
- Likelihood of scientific/ medical advances within foreseeable future that will improve the daughter's condition, or less drastic sterilization procedures would be available?

**Knowledge +  
Understanding +  
Voluntariness =  
Informed Consent**

# SEXUAL ABUSE

## Occurrence

- People with intellectual are 1.5 times more likely than peers to be sexually abused
- 83% of victims with DD are female
- 17% of victims with DD are male

## Who are the abusers?

- Caregivers! Only 6% are strangers

# SEXUAL ABUSE

## Why do they abuse?

- Physically attracted to children
- Power
- Stress (loss of job, divorce, etc.)
- Reduced risk of being caught/ opportunity
- Justification (“they want / need sex”)

# SEXUAL ABUSE

What do I teach my son or daughter?

- Personal safety and resistance (how to say “NO”)
- OK touch versus “uh oh” touch
- “My body belongs to me. Nobody touches it unless I want them to, and if it won’t cause any trouble.”
- Proper terms for body parts (assists in understanding reports)
- “Touching” secrets are not OK!”
- Family privacy boundaries
- When threatened, who do I tell?

# DILEMMAS

- “How can I tell whether my son or daughter has been sexually abused?”
- “I don’t want my adult son or daughter with SMS to be involved in a sexual relationship.”
- “My son’s / daughter’s frequent masturbation is upsetting to our family.”
- “I’m afraid my teen’s heightened sexual interest will get him into trouble if he says or does something inappropriate!”

# THE FACTS

- Most males with FXS experience puberty at the same time as typical peers
- Some females with FXS experience premature puberty
- All people with FXS are sexual beings regardless of their cognitive limitations
- Most people with FXS show an interest in sexual content, movies or relationships

# THE FICTION

- People with FXS do not experience typical sexual needs and desires
- Adults with a full mutation do not marry, have sexual relationships or seek pleasure
- People with FXS are sexual perpetrators
- People with FXS cannot be taught responsible sexual behavior

# Changes in Our View of Sexuality in the Developmentally Challenged

- Shift from *Protect* and *Defend* to *Prepare* and *Support*
- *Proactive* rather than *Reactive* intervention
- Inclusion requires appropriate sexual behavior
- Acceptance of those with FXS requires the ability to discriminate between private and public behaviors

# SEX EDUCATION

- Begins at birth
- Children learn about sexuality from their parents, the media and peers
- People with FXS often pick up on sexual behaviors and language due to the responses
- Remember that behavior that may be funny or cute at an early age, is not cute when the child becomes an adult

# Sexual Behavior Results From Interaction Between Biology and Environment

- BIOLOGY
  - Normal biological urges, associations and motivation
- ENVIRONMENT
  - The environment shapes our sexual behavior.  
Religious values, family norms and cultural expectations influence our sexuality
  - The response from family members or caregivers shapes the behavioral reaction from the person with FXS

# How to Reduce the Risk of Exploitation or Abduction

- Know your neighbors
- Identify community workers; postman, delivery persons
- List all persons allowed in the home
- Map out danger zones in the neighborhood to include registered sex offenders
- Keep your child's name out of plain view
- Provide an ID bracelet that has some code to identify your child
- Never assume someone is monitoring your child in a large group

# Sexuality in Females

- Because females are usually less affected than males with FXS, a number of challenges present
- Females tend to engage in sexual behavior more often than males
- Females enter long term heterosexual relations more often
- Females are more often exploited sexually

# Sexuality in Females

- Females are often naïve to the motivation behind seemingly interested males and run the risk of being manipulated
- Females can misperceive intentions and get hurt emotionally
- Females tend to over fantasize sexual relationships “in love with being in love” which can result in heartbreak and mistrust of future relationships

# Sexuality in Males

- Males can become obsessed with a relationship or just the thought of having a girlfriend
- This obsession can result in a dependence on a girlfriend
- Shyness and social anxiety can preclude acting on an interest in a girl in a direct manner
- Males often meet their sexual needs viewing pornography or adult entertainment

# Navigating Sexuality

- Grooming and maintaining hygiene become more important in order to build friendships and attract others
- Sexual curiosity often triggers embarrassment due to immature social/sexual reactions
- Often shut down emotionally when asked about sexual urges, fantasies or relationships
- Unable to understand subtle sexual innuendos, advances and behaviors

# Teach Prosocial Behavior

- Discriminate between appropriate and inappropriate behavior

✦ unzipping pants in public

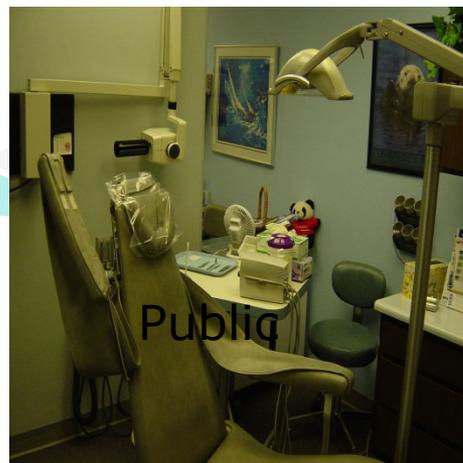
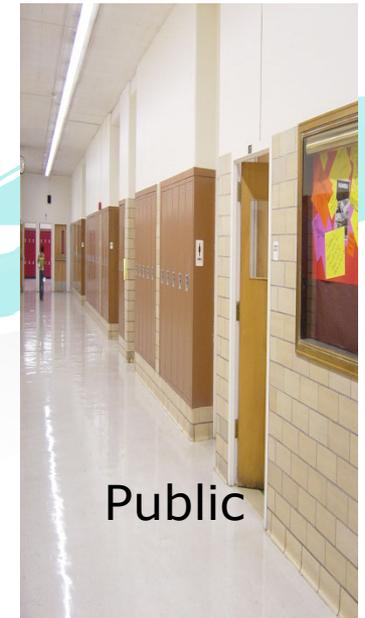
✦ exposing private parts in public

✦ using sexually explicit language  
in public

# Teach Prosocial Behavior

- **Teach basic concepts of Private and Public Behavior, Places and People**
- **begin early**
- **model appropriate sexual behaviors**
- **use repetition to habituate appropriate behaviors**
- **teach advocacy and self defense**
- **participation in social skills groups**

# Teach Prosocial Behavior



# Social Compass Program



JUL 15 2006

# Level 1 spinner and cards



# Level 2 spinner and cards



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# Social Compass Level Two



# Predictors of Independence

- Encourage a variety of experiences within the home community
- Develop interests and “common denominators” that make them more viable social partners
- Encourage social engagement in small groups such as church activities, scouting or clubs
- Encourage age appropriate dress, interests and activities
- Encourage grooming and personal hygiene

# Common Vocations and Interests

Females: Child Care, Working with Animals,  
Cosmetology/Fashion

Males: Cooking, Meal Preparation, Food  
Service, Gardening, Refuse Collection,  
Outdoor Work and Farming

Common Interests: Music, Sports, Current  
Events, Movies, Family and Collections

# RESOURCES

- Fitting In and Having Fun, Training Vol. 2: Moving on to Middle School – [www.difflearn.com](http://www.difflearn.com)
- The National Fragile X Foundation's Adolescent and Adult Project: Smoothing the Transition to Successful Adulthood
- Community Success CD

# RESOURCES

## FOR PARENTS

The Facts of Life...and More. Sexuality and Intimacy for People with Intellectual Disabilities. Leslie Walker-Hirsch, 2007.

I Openers: Parents ask Questions about Sexuality and Children with Developmental Disabilities. David Hinsburger, 1993.

Sexuality: Your Sons and Daughters with Intellectual Disabilities. Karin Melberg Schwier, 2000.

Sexuality and Your Disabled Child: For One and All. Sue McLeod, 1985.

## TRAINING AND EDUCATION

Social Compass: Tools for Navigating Life, Marcia L. Braden, Ph.D., 2007.

Circles: Intimacy and Relationships, James Stanfield Co., 1993.

The Facts of Life and Living: A curriculum that promotes social and sexual awareness for persons with disabilities. Linda Colley & Linda Howden, 1988.

LifeFacts 1: Sexuality and LifeFacts 2: Sexual Abuse Prevention. Nancy Cowardin and James Stanfield, 1989.

# RESOURCES

STARS: Skills Training for Assertiveness and Relationship-Building and Sexual Awareness. Susan Heighway and Susan Kidd Webster, 1998.

STARS 2 for Children: A Guidebook for Teaching Positive Sexuality and Preventing Sexual Abuse for People with Developmental Disabilities. Susan Heighway and Susan Kidd Webster, 1993.

The Ethics of Touch, David Hingsburger and Mary Harber. 1998.

First Contact: Charting inner space with people who have significant disabilities. David Hingsburger, 2000.

Just Say Know!, David Hingsburger. 1995.

Power Tools: Considering Power. David Hingsburger, 2000.

Socialization and Sexuality. Winifred Kempton, 1998.

Talking Sex! Practical approaches and strategies for working with people who have developmental disabilities when the topic is sex. Lisa T. Maurer, 1999.

**Questions?**