SEXUALITY AND FXS

Marcia L. Braden, PhD

Sexuality is an important aspect of development in all people. Individuals with FXS experience normal sexual development but without the cognitive, emotional or pragmatic structure necessary to consistently demonstrate socially acceptable behaviors.

Individuals with FXS require an intervention model that is significantly different from than their typically developing peers. For individuals with FXS, traditional sex education is too limited. Instead, a broader based social-sexual curriculum introduced at an early age and through varied developmental stages is necessary.

A sound social sexual model identifies a specific acquisition of skills necessary in order to be successful in and out of the community. Of particular importance is the ability to identify public and private behaviors. This rule-based structure provides concrete examples of behaviors that are classified by the individual as being either public or private. The chart below illustrates examples of how the model works.

BEHAVIOR	
Public Behavior	**Private Behavior**
• Blowing your nose • Holding hands • Talking on the telephone • Dancing • Handshakes • Hugging • Putting on lipstick • Combing hair • Eating	• Wearing pajamas • Urinating, having a bowel movement • Masturbating • Taking clothes off • Changing underwear, pull ups • Flatulation • Kissing • Taking a bath or shower • Intimately touching others • Cursing
LOCATIONS	
Public Places	**Private Places**
• Public bathrooms (school, church, restaurants) • Theaters • Restaurants • Living rooms/common rooms • Buses and public transportation • Classrooms • Automobiles • Stores, shopping malls • Church, synagogue	• Bathroom at home • Bedrooms • Hotel rooms • A private place with a door closed • Doctor's office/examining room
PEOPLE	
Public Acquaintances	**Private/Family and Familiar**
• Handshakes • Verbal greetings • High five	• Hugs • Arms around each other • Kisses • Touches

The chart that follows highlights a variety of social dilemmas along with concrete remedies or strategies. Generally, these issues present throughout the life span at varying degrees of intensity depending on the mental age of the individual.

SEXUAL DILEMMAS	STRATEGIES
Normal biological development; sexual interest can be chronologically age-appropriate.	Use visual and concrete sex education programs.
Difficulty with impulse control poses a serious threat to appropriate sexual contact.	Use age-appropriate models to teach appropriate interaction, touch, etc. Refer to physician for medication to explore a pharmacological remedy for impulse control.
Intimate relationships are often distant due to sensory deficits and aversion to touch.	Participation in social skills training. Desensitization of tactile defenses using OT strategies and calming methods.
Dating, telephone contact and setting a plan often becomes too demanding and can result in withdrawal and avoidance.	Practice ways to communicate that require less intense contact (writing notes, sending pictures, share the responsibility) with the other person in the relationship.

Social sexual development is far reaching because it forms the basis for successful interaction and subsequent expectations as a functioning adult. Although an individual with FXS may be cognitively delayed, it is imperative to stress age-appropriate behavior throughout the life span. Even though it may seem innocent for a three-year-old to run through the yard naked, that same behavior if gone unchecked can be construed as indecent exposure as a teenager. The chart that follows describes typical behavior for individuals with FXS and social sexual skills for the corresponding age.

DEVELOPMENTAL MARKERS	SOCIAL SEXUAL SKILLS
Preschool (3-5 Years)	
• Highly social: wants to interact; observes others, but usually from a safe distance. • Initiates social interaction: may greet others, "hi man, hi boy." • Environment: easily provokes anxiety resulting in overstimulation. Typical defenses are tantrumming, dropping to the floor, making perseverative noises, chewing on clothing, mouthing objects, turning head, hiding behind hands, or a parent's leg. • Hypersensitivity to sound, lighting, touch and routine, which may trigger a panicked reaction.	• Keeping private parts private. • Polite bathroom behavior. • Using public bathrooms. • Toilet training with door closed. • Teaching knocking before entering a closed door (private). • Dressing and undressing. • Bathing with the door closed. • Grooming, washing hands, brushing teeth. • Introduce calming techniques when signs of being over aroused are seen. • Wearing sunglasses, chewing on licorice, thera-tubing or gum. • Identify a signal or family code to summon assistance when panic occurs.

DEVELOPMENTAL MARKERS	SOCIAL SEXUAL SKILLS
Elementary School (5-12 Years)	
• During this stage, child may be more aware of differences in ability as compared to typical peers.	• Sexuality is part of who you are. • Identifying body parts in males and females.

• As social awareness: improves, one may be precluded from interaction thus feeling left out. Lacks language skills to express emotional disappointment. • Large rooms (gymnasiums, auditoriums, malls) provide excessive sensory stimulation. Noise becomes a significant source of distraction and anxiety, resulting in acting out and aggression. • Nighttime anxiety and fear of going to sleep may cause the child to perseverate on break-ins, TV programming, or movies. • Schedule and routine changes, spontaneous plans, new people, and travel may cause anxious reactions triggering panic. • Reliance on certain individuals for safety and reassurance. • Coping strategies are slow to develop due to higher-level cognitive deficits. Negotiating, understanding abstractions and decision-making are difficult. • Poor reasoning skills due to sequential processing deficits may cause one to get stuck on a point, which triggers obsessive tendencies that interfere with flexible thought process.	• Understanding reproduction (answer questions as they are asked). • Practice decision-making strategies. "What's the right thing to do when ____" • Talking with family about sexuality, body development, pubic hair, breast buds, erections. • Avoiding and reporting sexual abuse and exploitation. • Grooming to now include more frequent showers, using deodorant, washing face, brushing teeth and using mouth wash or breath mints, etc. • Begin social skills classes or therapy to practice negotiation, using polite markers and variety in conversational exchange. • Use visual cues, sentence strips and social stories to depict particular sexual dilemmas and solutions.

DEVELOPMENTAL MARKERS	**SOCIAL SEXUAL SKILLS**
Adolescents (13-18 Years)	
• Male/female attraction continues to develop. The need for sexual contact also increases. • Sexual experiences may be affected by tactile defensiveness. • Sexual curiosity triggers embarrassment due to social reaction to sexual behaviors. • Masturbation seems to be common at this stage. Normal sexual excitation is common. • Natural biological urges persist. • Enjoys hearing typical peers talk about girlfriends and dating, which fosters sexual fantasies. • When girls initiate contact it may become too intimidating and overwhelming.	• Understanding the need for medical attention: breast exams, testicular exams, etc. • Becoming aware of body sensations and awareness of physical changes. • Grooming and maintaining hygiene become more important. • Practice appropriate communication about dating, courtesy and respect for the opposite sex. • Practice impulse control, using guided exposure and role playing. • Understand reproduction and pregnancy by providing details about community resources. • Understand taking responsibility for parenthood. • Discuss sexually transmitted diseases: Stress the use of condoms, abstinence and birth control. • Discuss sexual intercourse, masturbation and the risks of engaging in indiscriminant sex. • Teach privacy and sexual modesty. • Videotape interaction and play back for discussion.

DEVELOPMENTAL MARKERS	**SOCIAL SEXUAL SKILLS**
Adults (19+)	

• Often unable to maintain a relationship for an extended period. • Using the telephone is difficult: forgets to give messages, dislikes returning phone calls or making calls to set a plan or date. • Shuts down emotionally when overwhelmed by the demands of a relationship. When overwhelmed, may withdraw and become isolated in order to cope. This is often perceived as rude or self-centered. • Difficulty understanding social interaction, demonstrating empathy or meeting emotional needs of others; lacks theory of mind. • Gets over relationship break-ups quickly and easily. • Obsesses about comments made by others, forms fantasy relationships.	• Encourage group therapy, marital therapy, and individual therapy. • Practice making telephone calls to friends and family members. • Join support groups to enhance communication efforts and social contacts. • Participate in church groups, singles groups and small interest groups/clubs. • Referral to physician for medical advice related to birth control options. • Referral to psychiatrist for pharmacological treatment and medication.

There are a number of social sexual behaviors necessary for self-actualization. Because the process is ongoing, these behaviors should become objectives for IEP's and IHP's. These objectives are as important as any academic or vocational objectives and should be discussed thoroughly before a Transition meeting.

- Learn how to self-advocate.
- Develop interests outside the school environment.
- Attend musical or athletic performances.
- Attend dances or activity nights at school and in the community.
- Participate in appropriate sex education classes.
- Learn to discriminate between behaviors that are public and private.
- Establish relationships based on mutuality.
- Maintain grooming, personal hygiene; appropriate dress and positive body image.
- Develop ways to cope with embarrassment, humiliation and unfairness.
- Identify obsessive traits and learn how to reduce them.
- Expand social reciprocity within a variety of relationships.
- Imitate age appropriate social behaviors.
- Replace less desirable behaviors (hand flapping when excited, pushing finger against mouth) with alternative responses.
- Respond appropriately to persuasion and resist negative pressure to conform.

The issue of sexuality is not a new one. As we pave the way for individuals to be included in our communities, we must support them through sex education programs. It is critical to teach relationship building. This process happens automatically with typical peers, but for individuals with FXS, it is not automatic. We must teach each step of the process using clear and pragmatic examples.

There is no easy way to get from the toddler to adolescent stage without hitting roadblocks. The commitment to such a program is arduous. But if the focus is direct, it is reasonable to expect pro-social behavior and personal respect within the individual with FXS. It is no longer appropriate to excuse maladaptive behavior based on cognitive deficits because our vision has shifted from segregation to inclusion. It is far more dangerous now to allow inappropriate sexual behavior to remain unchecked. The correction procedure must be utilized 100% of the time and the positive outcome reinforced consistently. When effective programs are used in all environments, the end result offers more opportunity for the individual with FXS to gain access to community based and independent living.