Sexuality and Fragile X Syndrome

An Overview for Parents, Families, and Professionals

Amanda Bergner, MS, CGC       Marcia L. Braden, PhD
Deborah Kwan, OTR/L            Ellen Walters, MFT

Sexuality is a natural part of life. It includes emotional development and social behavior, body image and awareness, self-esteem, friendships, gender identity, as well as involvement in physical expressions of love, affection, and desires.

Like their typical peers, individuals with developmental delays or disabilities have sexual feelings, needs, and identities. Unfortunately, myths about people with disabilities and sex abound. One such myth is that people with disabilities are either not interested in sex or are not capable. At the other end of the spectrum, people with disabilities are sometimes viewed as being overly interested in sex and unable to control their sexual behavior.

In reality, individuals with fragile X syndrome (FXS) develop the same physical and sexual characteristics as those without FXS (hair growth, breast development, menstruation, and other physical changes). Males with FXS are capable of fathering children; females are capable of conceiving and bearing children.

Young adults with FXS must have access to socialization, sexual education, sexual health care, and opportunities for developmentally appropriate socializing and sexual expression to help them understand and enjoy their sexuality. The ability to maintain friendships, share interests, and be included are deep human needs. Individuals with FXS have the same basic need to be liked and accepted as their peers.

Sex education for adolescents affected by FXS needs to be somewhat different than it is for their typically developing peers. Generally, the education will need to be broader in scope and continue over an extended period of time. The individual must have numerous opportunities for developing and understanding the appropriate time and place for certain behaviors, such as the display of affection. Just as self-help, academic and vocational skills must be taught, so too must social-sexual skills.

Sex education and socialization skill development should begin when children are young. It should make clear the difference between “good” and “bad” touch and behaviors that may be acceptable
in private but not in public. Moreover, individuals with FXS have a need for sex education that continues through and well beyond puberty. It is also important for parents to explain the concept of values and beliefs in general, and the ones held in particular by their family.

Psychosocial issues also require attention. At any age, relationship failure can occur because of a perceived lack of interest, self-centeredness, social immaturity, shyness, anxiety, agitation, and eye-gaze aversion. These are all characteristics that can be exhibited by individuals with FXS, and which can affect the process of developing meaningful relationships. Early, consistent, and repetitive attention to socialization skills and sex education can reduce the incidence of relationship failure.

Protection from unwanted pregnancy and sexually transmitted diseases is also a critical component of sexuality education for adolescents and adults with disabilities.

These individuals are disproportionately vulnerable to sexual abuse and manipulation. Consistent with a family’s cultural and religious beliefs, prevention information and supplies should be readily accessible.

There are a number of programs available to educate individuals with developmental disabilities about safe sexual involvement. Parents are encouraged to contact the resources listed herein and to consult with trusted medical, mental health and spiritual advisors. As much as is practical, parents should be involved and continue to counsel their children throughout the various stages of psycho/social/sexual development.

Sexuality and sexual development can be difficult issues for individuals with FXS and their families. Appropriate sexual behavior and compliance with cultural and social norms and laws are achievable goals for all individuals with FXS. By addressing these challenging issues, we can help individuals with FXS to become productive, accepted and fully included members of our communities. At the same time, it is necessary to encourage society to validate the overall development of individuals with FXS, including their sexuality, as a fundamental right, and as part of the process of becoming a complete and mature human being.

Finally, moral and religious beliefs dictate much about how information relating to sexuality is passed from parent to child. The information here is designed to address issues raised by the unique characteristics many with FXS share, and to direct the reader to additional resources. To establish a solid foundation of socially appropriate behavior, it is recommended that sex education for individuals with FXS begin at an early age.

Also, please note that The National Fragile X Foundation has created a pamphlet that covers much of this material. It is available free of charge—call 1-800-688-8765, or email NATLFX@FragileX.org for more information.
SUGGESTED SEX EDUCATION CURRICULUM

Following is an overview of the topics that should be included in a sex education curriculum.

• Health-related information
• Anatomy
• Gender identification
• Routine male and female examinations
• Anticipated changes in the body such as hair growth, breast development, and menstruation
• Disease prevention
• Sexually transmitted diseases
• Safe sex
• Appropriate social/sexual interaction
• “Public” versus “private” behavior
• Exposing private parts
• Touching self and others
• Masturbation
• Mechanics of sexual intercourse and sexual stimulation
• Reproduction and parenting
• Birth control
• Procreation and pregnancy
• Inheritance of fragile X syndrome
• Care of a child (possibly with special needs)

Clear information on all these topics may help prevent legal situations and abuse.
For Women: A Strategy for Dealing With Sexual Advances
Developed by the Project Work Group

This information describes one way to help a woman deal with sexual advances from men. Olivia and her helper are talking about Olivia’s date the night before.

Olivia: I didn’t have a good time with Tim last night.

Helper: Do you want to tell me what happened?

Olivia explains that after their movie date, Tim asked if she wanted to go to his friend David’s house. She was reluctant because she doesn’t know David. Still, instead of saying no, she said she didn’t care. At David’s they all watched TV and Tim held her hand. Tim asked if he could kiss her, and Olivia got nervous.

Olivia: He kissed me and I started giggling. Then he put his hand in my pants. I was so scared—I didn’t know what to do.

Olivia said that David’s mom entered the room and Tim moved away before she saw what was happening. He then took Olivia home.

Helper: You know what? Sometimes I have the same problem. When I get nervous, I start to laugh and the guy I’m with thinks I like what he’s doing. I’ve had a guy get really mad because I stopped him from touching me.

Olivia: What did you do? Did you stop dating?

Helper: No. I learned to make myself relax. Now, when I get nervous, I start deep breathing and it helps me to calm down and I don’t laugh. Then I can tell him what I want and don’t want.

Olivia: I want to try that. How can I learn about deep breathing?

Helper: I learned it from a book, and I also got a CD that explains how to do it. You can buy it at a bookstore, or you can borrow mine.

Helper: I’m glad we talked.

Olivia: Me, too.
Public vs. Private Behavior: Masturbation

Developed by the Project Work Group

Adolescents with fragile X syndrome experience sexual arousal just as all adolescents do.

Mother: I’ve seen Will put his hands in his pants a lot more recently.

Father: I’ve noticed that too.

Mother: We had to leave the mall yesterday because it got so bad.

Father: It could be a problem if he starts doing that at school or around the neighborhood.

Mother: At the last Fragile X conference, I went to a session where a speaker talked about sexuality, and she said that boys are going to do this.

Father: And? What should we do?

Mother: The first thing she said was: Don’t overreact.

Father: It’s hard not to when we’re in public.

Mother: I know. This is part of normal development, part of life… it isn’t something he’s going to grow out of.

Father: And it isn’t something that can be stopped with a behavior program or medication.

Mother: I think we should talk to Will and let him know that it’s okay to do, but only in private.

Father: I’ll talk to him.

Later that day…

Father: I told Will that he has grown to an age where some parts of your body get sensitive and feel good to touch. He was a little embarrassed, but I told him it’s a normal part of growing up and everyone has the same feelings. But I stressed that it isn’t okay to touch yourself in public; it has to be in private.

Mother: What did he say?

Father: He asked if it was okay to do in his room and I told him either there or in the bathroom were both okay. I didn’t make a big deal out of it, and I hugged him and let him know we’re with him on this, and we’ll help him.

A week later…
Mother: I’ve only had to remind him a couple of times. I think your little talk helped.

Father: He is doing much better.

_It may not be this easy with all adolescents, but it is important to address it as often as needed so it does not become a serious problem._
ARTICLES ON SEXUALITY EDUCATION

The following pages are reprinted from a two-part series titled “Sexuality Education: Building a Foundation for Healthy Attitudes,” which appeared in Volume 4, Issues 5 and 6, of Disability Solutions magazine. They were written by Terri Couwenhoven, MEd, and are reprinted with permission. Disability Solutions is published by:

Creating Solutions
1435 Westlake Dr., Ste. A-2
Lake Oswego, OR 97035

Creating Solutions is a 501(c)3 public charity.

The articles were written for children/young adults who have developmental disabilities; they are not specific to fragile X syndrome. While some of the information is geared towards young children, you may find that it is still applicable to your situation with your adolescent or young adult, now and in the future.
We all have those moments. Those moments when something happens and we try to figure out why we reacted a certain way. By the time they are over, we are forced to understand something about ourselves we didn’t realize before. I had one of those moments a few months ago. My 11-year-old daughter with Down syndrome asked me, “What is sex for?” For any other parent this might not have been a memorable moment. For me, a sexuality educator, it was the moment. In those silent seconds following her question, my mind was moving like a ping-pong ball in a tournament match. Who had been talking to her about sex? Did her sister use some terminology she wasn’t familiar with? Was there a movie that I missed censoring? No they were well hidden.

I’m not sure how much time went by before I asked in a pleasantly inquisitive voice, “Where did you hear that word?” She shrugged.

“Okay,” I thought, “I’m a sexuality educator, I can tackle this one. I have resources. I have information.”

“Mooomm, what are the socks for?” she asked.

This time she said something different. At that moment I noticed the socks I had thrown on my shoulder while folding wash. I was relieved. It was like a deadline for a project that was nowhere near completion, my time had been extended. But I did learn something looking at some of my books? No they were well hidden.

I’m not sure how much time went by before I asked in a pleasantly inquisitive voice, “Where did you hear that word?”

She shrugged.

“Okay,” I thought, “I’m a sexuality educator, I can tackle this one. I have resources. I have information.”

“Mooomm, what are the socks for?” she asked.

This time she said something different. At that moment I noticed the socks I had thrown on my shoulder while folding wash. I was relieved. Like a deadline for a project that was nowhere near completion, my time had been extended. But I did learn something

Continued on page 3
I’ve yet to meet a parent who doesn’t cringe if the topic of sex education comes up. Somehow our children, with or without disabilities, are forever our children. Teaching them about relationships, bodies, and sex is tough for most. In this issue of Disability Solutions, Terri Couwenhoven shares the first of a two-part series on sexuality education. This first article offers tips for building a foundation of learning healthy attitudes about privacy and other concepts that are later woven into our children’s ideas about relationships and sex.

I found this first installment particularly interesting. I’ve long felt that there was little for me to do at this point for my son. I was wrong! I was glad to find some of the things we were already doing were important points in teaching a child their body is their own—even when they need some assistance. I also find Terri easy to talk to regarding sexuality education. Not only is she professional, but she is also a mother of a girl with Down syndrome. She understands from a professional point-of-view and because she lives with similar challenges. It is comforting not to have to explain some of the nuances of Down syndrome when coping with a tough, private topic such as masturbation or birth control.

In part two of this series, Terri shares information for building on the foundation of sexuality education. It will be a great source of information for those of you with teenagers and adults in your life.

We also want to thank all the children and young adults who are featured in this article.

Pages 3, 9, 11, and 13
Anna Couwenhoven, Port Washington, Wisconsin
Page 3
Alex Krupski, Grafton, Wisconsin
Page 9
Lucas Rilling, Saukville, Wisconsin
Page 11
Front Row: Malorie Ott, Nicole Bliesner, Lindsay Wanta
Back Row: Anna Couwenhoven, Katelyn Rekoske, Caitlyn DeKarske
All from Port Washington, Wisconsin
Page 13
Lindy, Terri, and Anna Couwenhoven
About myself that day. This sexuality stuff, is not easy. And talking to other people with developmental disabilities, other families, or other professionals who support people with disabilities is different than talking to my child. Up until that point, I had felt pretty good about the progress Anna had made on her journey to becoming a sexually healthy person. But I had to keep moving. There was so much more she needed to know.

Moments like these remind me why I enjoy teaching parents, professionals, and self-advocates about sexuality. This is the first of a two-part series about sexuality education for parents of children with developmental disabilities. It will outline the importance of early sexuality education and explain the first layer of topics to introduce to your child. Part two will expand on this foundation to issues for parents of teenagers and adults with Down syndrome.

When I attempt to define sexuality with parents or professionals in programs, it isn’t an easy task. What makes it difficult is that sexuality is such a broad term encompassing so many facets of who we are. Sexuality involves our beliefs and feelings about being male or female and the roles and expectations associated with them. It involves our behaviors, interactions, and relationships with others of the same and opposite sex. It includes how we feel about our body and ourselves. Sexuality is a process of learning that evolves throughout our lives, an active, inseparable part of who we are.

Sexual Learning: How it Happens & Why it Needs to Happen

Parents are the primary sexuality educators of their children, which is how it should be. From birth, we model and teach our children messages about love, affection, touch, and relationships. How we cuddle and hold our children teaches them how we feel about them. Some believe loving touch early in life sets the stage for healthy adult intimacy.

Who we are as a sexual adult is largely a result of how we received information as children. For most of us, learning about sexuality occurred in a variety of ways. Our parents were likely our primary sexuality educators, as they are the initial and most frequent teachers and models. Later our peers, the media, religion, and life experiences influenced our sexual learning.

For people with disabilities such as Down syndrome, opportunities for learning about sexuality are more limited. The reading level of materials is out of reach, which limits access to quality printed materials and resources. Even though we, as parents, understand the importance of creating opportunities for socialization, opportunities for our children with Down syndrome are scarce. As a result they have fewer chances to observe, develop, and practice social skills, which are particularly important in early and late adolescence. The subtle messages, looks, and innuendoes that are bantered between pre-adolescents and teens on television and in school are often lost for our children. They may have
Continued from page 3

trouble making decisions and thinking realistically about situations. All of these factors underscore the need for sexuality education much more than the general population.

Studies tell us what parents already know: the risk of exploitation among people with developmental disabilities is greater than for those without. Some of the reasons for this include:

- Children with developmental disabilities are more likely to be dependent on others for meeting their basic needs because of the nature of their disability;
- Children with developmental disabilities may have learned to be compliant or passive, especially with authority figures;
- Children with developmental disabilities sometimes don’t have social skills needed for the situation;
- Children with developmental disabilities may have trouble with reasoning and judgment; and
- Children with developmental disabilities are exposed to larger numbers of caregivers than their nondisabled peers.

Each of these factors increases the vulnerability of your child to some type of exploitation or abuse.

Even though the need is greater, many parents avoid or postpone addressing sexuality issues until it is too late. There are many reasons for why this happens including:

- Their own sexual learning process. Some parents had poor role models for teaching and learning about sexuality.
- Age or generation of the parent. Parental attitudes about sexuality education usually mirror the attitudes of society during their childhood.
- Availability of resources and supports. Parents are easily overwhelmed with the day-to-day issues that go along with raising a child with a disability. Sexuality issues are easy to place on the back burner. Once they are ready, there are few community resources making getting help with teaching about sexuality and related issues difficult.

Disability of the child. In my experience as a sexuality educator, the abilities of the child directly affect whether the parent sees the child as being sexual. Often, the more severe the disability, the less likely parents feel the need to address sexuality issues.

Proactive Sexuality Education

Too often for families with children with developmental disabilities, teaching sexuality revolves around crisis situations. I frequently receive calls from frantic parents whose child was kicked off the bus for inappropriate touch. Or calls from school staff wanting programs focused on solving a similar problem rather than addressing the broader sexuality issues of the individual before a problem occurs. Some ideas for teaching about sexuality are addressed later in this article.

All children begin their lives as sexual people and teaching about sexuality should occur throughout life. Children with developmental disabilities are no exception. Providing information and addressing issues at younger ages allows you to reinforce concepts over longer periods of time in a wider variety of real-life situations.

More and more parents are being asked to think long term about goals and expectations for children with disabilities. When we are aware of the normal sexuality issues likely to emerge at various stages of our child’s life we can more easily identify expectations, visualize goals, and be proactive about requesting assistance before problems arise.
Sexuality Education: Building a Foundation for Healthy Attitudes

Collaborative Teaching

Although parents are likely the most influential and consistent teachers of sexuality, other professionals inevitably become involved in communicating sexuality messages as well. Often in programs I share with professionals and parents a sexuality education triangle to help them remember the importance of collaborative efforts in this area:

Sexuality Education Triangle

The triangle represents an ideal situation: parents and professionals working together to support the person with a developmental disability in moving towards sexually healthy adulthood. Even in this ideal situation, the road that needs to be taken is a difficult one. The journey requires both parents and professionals examine their own values and attitudes on a variety of sexuality issues. This is often a painful process. A parent I know was very upset when she discovered the school her son attended allowed her son to masturbate in a private bathroom with the door closed when it was not something he was allowed to do at home. Different values? Absolutely. Confused kid? Probably.

Effective parental roles within the triangle include:

- Understanding personal values and communicating them to others who are supporting the child,
- Sharing home approaches for dealing with inappropriate sexual behaviors,
- Identifying teaching strategies that have worked best for their child or adult, and
- Pinpointing where learning difficulties typically occur.

Most families are able to share examples of successes and difficulties they have experienced in the process of teaching their child about sexuality. When shared, parents and professionals can use them in sexuality teaching sessions to improve the relevance for your child.

Professionals supporting the person with a disability have an important role in teaching sexuality education as well. Often they have access to materials designed specifically for people with disabilities that are cost prohibitive for most families. They can design alternative teaching techniques for addressing sexuality issues, help families identify resources within the community, and supplement and reinforce sexuality concepts within community environments.

Finally, it’s important to remember the person with the disability is at the top of the triangle for a reason. It is to remind us that the needs of the individual should be at the forefront in developing and implementing sexuality programming and should encourage ongoing, open dialogue between families and professionals.

The Early Years: Key Concepts and Issues in Sexuality

Sexuality information and teaching shared during your child’s early years provides the beginning of a foundation that will need to be repeated, supplemented, and reinforced

Continued on page 6
Continued from page 5

as your child grows. This foundation provides a base from which to build, and interface with more advanced sexuality concepts are taught and your child matures. For example, it is more difficult to teach the physical changes that accompany puberty if your child does not have vocabulary for the genitals.

Teaching About the Body

All young children are naturally curious about their bodies and how they work. Children with developmental disabilities are no different. Teaching them about their bodies, including the sexual aspects of their bodies, should begin early. Early and open (but private) discussions about these issues are more likely to eliminate the guilt, shame, and negativity that is often associated with the body and genitals and set the stage for future discussions with your child as he grows older.

Helping your child use the correct words for genitals is one foundational aspect of teaching. It should be done around the same time your child is learning about other body parts and their functions. Teaching about private parts, however, should be done in the context of private places. For example, discussing genitals and their function in the middle of the living room is not appropriate in most situations. It makes more sense to teach during private bathing sessions. When your child is learning to identify eyes, nose, and fingers, he can also be learning penis, vulva, breasts, and buttocks. Professional literature suggests that when children have accurate language for private body parts they are more likely to report abuse if it occurs. When they do, they are more believable in the reporting process because of the vocabulary they use in their description.

Another piece of the foundation includes understanding body ownership and taking care of your body yourself. Teach your child about washing and caring for his body and private body parts. Remember to gradually reduce the amount of help you provide and give him the responsibility for washing and caring for all parts of his body.

When you teach your child about body parts, include information about societal rules associated with them. For example, in America, private parts always need to be covered in public places. Most children as they mature naturally develop modesty about their bodies. Children with developmental disabilities often have to be taught to be modest. You can encourage modesty early by wrapping your child in a towel and moving him to a private place to dress or change.

Identify private places within your home. This also means respecting your child’s desire to want to be in private when appropriate.

Once your child begins to appropriately use terminology and apply societal rules related to body parts, it is time to include phrases that prevent exploitation. For example, teach your child that his private body parts are off limits to others. Discuss with him circumstances or exceptions to that rule such as physicians, parents or grandparents during bath time, or other circumstances specific to your child. Emphasize to him the importance of reporting when respect for boundaries is being violated. Make sure he understands who to tell when his privacy or body is not respected.

Some other ways you can teach and support these concepts include:

- Read and share illustrated books with your child that have empowering messages about the body, body parts, and relevant societal rules.
- Use everyday teachable moments to reinforce foundational concepts. For example, if your child is dressing, remind him to
Sexuality Education:  
Building a Foundation for Healthy Attitudes

close his door for privacy. If your child exposes private body parts in a public area of the home, quiz or remind him of the rules related to private body parts.

Understanding Gender Differences
Becoming aware of the physical differences between male and female bodies is another block to the foundation of sexuality knowledge. Most parents have stories about their children’s natural curiosity regarding bodies leading to a game of “you-show-me-and-I'll-show-you” or “playing doctor.” For children with developmental disabilities or speech delays, this same curiosity will lead to the same, or maybe some different types of behaviors. As a young child my daughter attended an integrated preschool where the bathrooms were used by both girls and boys. Apparently she was aware of differences in urination styles because at one point I found her in our bathroom at home attempting to urinate standing up. Fortunately for me, I got to her before she completed her experiment. Needless to say, it was a teachable moment and an opportunity to share with her some information about being a girl and the differences between how boy and girl bodies work. Another mother had concerns about her son who would touch her breast unexpectedly, and at inopportune moments, when he was young. This may have been his way of expressing some curiosity about a body part he did not have.

Touching or Stimulating Private Parts
Let’s face it: many children discover fairly quickly what we know as adults, that touching your genitals feels good. Although the terms genital touching and masturbation are often used interchangeably, there are differences. At a young age genital touching is generally not purposeful or goal oriented, but instead a result of normal body exploration and curiosity. For some young children, touching their genitals offers a way to calm themselves, like before a nap or bedtime or during particularly emotional times such as a new baby or divorce. The term masturbation is used when genital stimulation is more purposefully intended as sexual pleasure or orgasm. Masturbation can occur before puberty. Some children may not engage in genital exploration or masturbation, which is normal as well.

The most common concern I hear related to this issue involves a child with a developmental disability touching his genitals in public places or at inappropriate times. When genital touching or masturbation occurs at inappropriate times and places, clear and direct messages need to be shared. Your child needs to know that touching his penis (or her vulva) is a private behavior. Therefore, the behavior requires him to be in or move to a private place, ideally his bedroom with the door closed. If your child does not respond to a verbal prompt, physically move him to his bedroom avoiding negative or punishing remarks in the process. Some children will have more difficulty being able to tell the difference between public and private locations. When private behavior occurs in public, share messages about the behavior not being appropriate in a public place and attempt to redirect your child to another activity. For more perseverative behavior (behavior that he will not stop once it’s started), there will be a need for more environmental controls and planning. Try to be consistent in how you respond.

Inconsistent responses in these situations are confusing for your child and decrease the effectiveness of your teaching. Don’t forget to rule out possible physical causes for the

Continued on page 8
Continued from page 7

touching (i.e., urinary or vaginal infections, uncomfortable clothing, chafing, irritation from soaps, detergents, etc.).

Privacy

For most people, privacy is not an issue. It is a personal right that’s taken for granted. If there are times you need to get away and be by yourself, you figure out ways to make it happen. You stay up later to have a private conversation with a significant other or get up a little earlier so you can have quiet time before the house erupts with activity in the morning. The point is, you understand and value the concept of privacy and its significance within your life.

For people with developmental disabilities, privacy is often seen as a privilege rather than a right. In addition, the rules of privacy are frequently violated by the people who support them. By adulthood, people with developmental disabilities are so accustomed to having their privacy violated they are desensitized to the word “privacy” and its meaning. This desensitization often results in difficulties in discrimination between public and private behavior and leads to inappropriate behavior within the community.

For these reasons the concept of privacy is something that must be taught early. For children without disabilities, privacy can be introduced as early as three or four years old. The same rule applies for children with disabilities. The best way to teach privacy is to model it. When my children were younger they were constantly ignoring my attempts at privacy. This is common, but difficult when you live in a small house with one bathroom. After thinking about this, I realized they were modeling my behavior. I needed to help them understand the importance of privacy for me and for them. I began modeling the behaviors I expected from them: I knocked on doors and waited for a response before entering anyone’s room. When they barged into my room, I asked them to knock. When they took a shower, I spoke through the door rather than entering the bathroom. If they needed help, I would help and then let them know I was leaving so they could be in private. We stopped talking about private things such as bodily functions in public places like the dinner table or the living room, a habit they learned watching their grandmother. Although my younger daughter grasped the concept of respecting a closed door, she would often observe the goings on in her sister’s bedroom by peering through the small glass windows of her antique door. She felt the need to report what her older sister was doing and offer her interpretation of why. I sewed some curtains to cover my older daughter’s windows and attempted to help my younger daughter understand the subtle ways she violated her sister’s rights to privacy. We still have a long way to go, but my daughter now verbalizes when she wants to be in private, a big step.

Last summer we experienced some regression in this area when my daughter began wearing her scoliosis brace. She learned very quickly how to remove it independently and did so whenever it was convenient. She’d hoist up her shirt on the playground in full view of whoever happened to be watching. This made sense after I realized we had not been careful about where and when we removed the brace at home. We revisited the issue of privacy with her and made sure that when she was removing the brace at home, she did it in the bathroom or in her bedroom with the door closed, which are her private spaces. We made sure the professionals who supported her understood our goals and fol-
Sexuality Education: 
Building a Foundation for Healthy Attitudes

allowed suit. Because she was familiar with the concept of privacy, her understanding of the rules related to brace removal made teaching much easier for all of us.

The need for privacy is developmental. Most children naturally develop some sense of modesty as their bodies begin to mature and, as they get older, their need for privacy and to be in private becomes more important. Respecting their changing needs for privacy is an important part of their developing independence.

Touch, Affection, & Boundaries
The importance of healthy touch and affection to healthy sexual development is well documented. Some mental health professionals suggest loving touch in early childhood creates the capacity for healthy adult intimacy later in life. Caring caresses, loving touches, and affection help children know how we feel about them and gives them a sense of worth and well-being.

Helping people with developmental disabilities understand the rules related to touch, affection, and boundaries is difficult. There are a variety of issues that contribute to this.

Children with special needs are used to having their boundaries violated at very early ages.

From early on children with developmental disabilities are involved in circumstances that may be different than the general population. Early intervention programs typically require the child participate in invasive therapies. For example, the physical therapist may manipulate your child’s trunk and limbs or the speech therapist may perform types of oral stimulation in and around her mouth. Outside of early intervention most parents have experienced acquaintances or strangers who feel the need to pinch cheeks, poke tummies, tug ear lobes, or give nondiscriminatory hugs to their child because “children with Down syndrome are so lovable and affectionate.” When children have their boundaries repeatedly violated in ways like this, even though well-meaning, they lose their sense of what is appropriate. Inevitably, they begin to violate the space of others.

Our society’s attitudes about people with developmental disabilities as sexual human beings is still distorted and problematic.

Myths regarding people with developmental disabilities as being “asexual,” “oversexed,” or “perpetual children” prevent others from teaching age-appropriate strategies for addressing touch and boundary issues. If parents or professionals perceive the person with a developmental disability as asexual, for example, they may believe that the person with a disability does not need information and training on appropriate touch and boundaries or other areas of sexuality. When people with disabilities are believed to be “oversexed” or “uncontrollable” the consequence is constant supervision and careful scrutiny and over-analysis of every sexual behavior or perceptions that the

Continued on page 10
individual requires more affection than the average individual. When an adult with Down syndrome is seen as a perpetual child, it prevents others from seeing the child as a maturing individual who needs skills to move them from childhood behavior to more age-appropriate behavior.

During a workshop I conducted, a mother discussed her 13-year-old son who was having some trouble inappropriately expressing affection. Later she shared that her son liked to sit on her lap at family gatherings. Her son was getting mixed messages about affection and boundaries, which created confusion for him. I’m not advocating we starve our children of affection and touch, but I am suggesting we begin to think of our children as sexual human beings who likely need more guidance and intensive instruction in this area than our other children need.

One day the guidance counselor from my daughter’s middle school called to discuss her gestures of affection with a particular boy in her class. Not long after I spoke with her about the incident I had to pick her up at school to go to a doctor’s appointment. After she had gotten her things together and began leaving the room, one of the male paraprofessionals insisted on one of those front-to-front bear hugs. I cringed and was amazed the other professionals in the room didn’t even flinch. Is it inappropriate for an adult authority figure to be bear hugging an eleven-year-old girl in a school setting? I believe so.

The rules for touch and affection are often fuzzy and change based on culture and context, making teaching hard and fast “rules” a difficult task. As a parent I struggle with this on a regular basis. When my daughter entered middle school I noticed an increase in physical affection toward her female friends. At the same time, like most kids this age, she was struggling in her attempts at fitting in. I stepped in (again) to help her identify other ways to let girlfriends know how she felt about them besides hugging. We talked about words and phrases she could use with friends that would reflect her feelings. We brainstormed a list of different types of touch that would work such as soft arm squeezes, high fives, hand on the back, and so on. Imagine my confusion and embarrassment when at her co-ed birthday party I observed the “nondisabled” girls hanging all over each other. I must say Anna was appropriately distant, yet in this context she looked out of place. I realized she had been modeling some of the touch and affection she observed in the hallways of her middle school. In the context of middle school with her female friends, her expressions of affection may have been appropriate.

Here are some additional tips for helping your child understand touch, affection, and boundaries:

- Set rules related to touch and authority figures as early as possible. Too often patterns of inappropriate affection and touch are ignored in early childhood leading to problems later on.
- Respect your child’s right to be discriminatory regarding who they display affection with regardless of who the other person is (relatives or professionals).
- Communicate your goals and expectations related to touch and affection with key support people. Use the triangle as a guide. Consistency in teaching and reinforcing rules related to touch and affection across environments will increase the likelihood of success.
- If your child displays affection indiscriminately, adopt a set of concrete rules that are easy to learn. For example hand-
Sexuality Education:
Building a Foundation for Healthy Attitudes

shakes, head nods, and verbal greetings are appropriate gestures for greeting authority figures. Choose one and use it consistently. Provide one or two alternatives for the inappropriate touch you are attempting to eliminate. Remember, we don’t want to eliminate touch and affection completely, but simply make them more socially acceptable.

David Hingsburger, a Canadian author and lecturer on sexuality, addresses modeling we can do for more intimate touch. In his book, *I Openers: Parents Ask Questions About Sexuality with Children with Developmental Disabilities*, he describes a four-step process for helping children differentiate between necessary, intimate touch such as physician examination, diaper changing, and hygiene assistance.

1) *Ask permission* before touching.
   Asking permission helps promote a sense of ownership. Develop a “private” tone of voice that is softer, gentler, and quieter than your speaking voice. If your child has limited verbal abilities, give them time to respond in their own way. Ask first, touch second.

2) *Describe* what you are doing.
   Using the same soft voice tones, describe what you are about to do, then talk while you touch. Explain what you are doing and why. This encourages your child to ask questions, feel involved in the process, teaches your child language about his body, and creates a sense of safety for him.

3) *Facilitate participation.*
   As parents, our goal for our child with a disability should be partial participation in the necessary touch. If you are teaching hygiene skills, for example, one of your goals could be to allow your child to do the washing while you talk through the closed shower curtain.

4) *Communication*—Talk to your child after the touch has occurred. Describe what you did, and why you did it. For example, “Together, we just washed your whole body, now you are clean and ready to start the day.” Discussing touch and feelings about touch paves the way for future discussions.

**Identifying and Communicating Feelings**

Within the context of sexuality education, being able to communicate feelings is an important interpersonal skill. For example, being able to identify and respond to the emotions of a friend or partner enhances communication and intimacy. This skill also provides a basis for discussions surrounding feelings about body changes and touch. Being able to recognize and respond to emotions is complex for most of us. People with disabilities struggle with this as well. Your child may have trouble expressing emotions, express emotions inappropriately, or misinterpret feelings in others.

You may need to teach your child how to label his feelings and respond to others’ emotions. You can do this by labeling your feelings more frequently, in a way that is genuine, and provide reasons for the feel-
lings: “I was frustrated that I forgot my lunch today.” Encourage your child to label his own feelings in association with an event. For example, “How did you feel when you won that race?”

My daughter and I used to play a game when she was small. I called it the “feelings” game. I would make an exaggerated facial expression and she would have to guess how I was feeling. For example, a yawn would indicate I was tired. A smile: happy. A hand covering a wide-open mouth, surprised. Then it would be her turn. She would fold her arms and wrinkle her face into a frown and I would guess the feeling she was trying to express. The idea was for this exercise to help her develop a “feelings” vocabulary, help her to cue into non-verbal facial expressions, and encourage her to verbalize her feelings when she needed to. As she became older, I would often model a feeling, ask her to guess how I was feeling, and then provide an explanation for why I was experiencing the feeling.

Social Skills

An important goal of early sexuality education is maximizing our child’s ability to confidently interact and relate to others. Understanding and being able to apply social skills is an important piece of that goal that often proves to be more challenging for children with Down syndrome. Learning and applying social skills typically requires concrete instruction and coaching throughout life.

Early social skills training begins with us, the parents. At very young ages, our children learn by modeling our actions and behaviors. We begin teaching manners, for example, by saying “please,” “thank you,” and “excuse me” in the presence of our children. Later we can encourage our children to practice the behaviors themselves in social situations. Gradually as our children are able to understand how their actions and words affect others, and why certain behaviors are appropriate and others are not, we begin teaching and coaching. Diane Maksym in her book Shared Feelings presents steps for helping you teach your child social skills:

- Decide on a specific skill you want to teach
- Demonstrate the expected behavior or response for your child.
- Practice or role play the behavior in a safe setting with supportive individuals or family
- Give your child feedback (i.e. where could improvements be made? What did he do well?)

Don’t assume that if your child can demonstrate a social skill in a practice setting, he will transfer that skill to a real-life setting. Many children with Down syndrome have difficulty generalizing skills and will need plenty of practice in real-life social interactions. The new social skill should be taught in a variety of settings with many different individuals.

When things do not go exactly as you had practiced, talk about the situation and reassure your child that it takes time to learn. Talk about what he might have done differently and try to begin and end your discussion with comments about what he did well in the situation. When your child successfully masters the skill, remember to reward and praise the behavior. Other strategies and resources that help reinforce and teach social skills include:

- Play time. For young children, play time is an excellent time to begin modeling and teaching social skills. For example, manners can be taught while playing with dolls or sharing toys.
- Social Stories. Social stories are simple narratives that teach responses to a social or problem situation. The stories, often used...
Sexuality Education: 
Building a Foundation for Healthy Attitudes

with children who have autism, include a descriptive sentence about the environment, a directive or appropriate response, and reactions of others in response to exhibiting an inappropriate behavior.

🔹 **Social Skills Board Games.** There are a myriad of games available that focus on teaching and practicing appropriate social skills (see resources).

🔹 **Role Plays and Sociodrama.** Role playing is a wonderful way to practice new social skills. It can be done with a group or more privately with just you and your child. Using Role play and sociodrama allows your child to explore different outcomes in social situations without lasting consequences.

These are some of the key components to building a foundation of positive, proactive sexuality education. As you can see, these concepts are not separate issues specific to sexuality but are important in other ways for your child such as developing a healthy self-esteem and improving communication. The activities are easy to include with other areas your child will learn when he is young. As your child grows, you can continue to build on this foundation and nurture your child’s understanding of who they are as a man or a woman. Part two of this series, *Building On the Foundation: The Adolescent and Early Adult Years*, will discuss sexuality education at home and at school for adolescents and adults.

Terri Couwenhoven, MS, is the mother of two daughters, one of whom has Down syndrome. She is an AASECT certified sexuality education consultant and Clinic Coordinator for the Down Syndrome Clinic of Wisconsin. You can contact by e-mail: tcouwen@execpc.com or by US Mail: TC Services, 209 N. Spring Street, Port Washington, WI 53074.

**References:**


Sexuality: Your Sons and Daughters with Intellectual Disabilities


From the time my daughter was born 18 years ago I have devoted much of my free time researching for information that would help her achieve milestones in her development, in all aspects of her development. When I had difficulty finding information, I would go to other parents with my questions. They, in turn, gladly shared stories, advice, and suggestions. That worked quite well until I asked questions about sex and sexuality. When I did, the silence from other parents was powerfully absolute. Sex and sexuality for people with disabilities is still taboo, still dreaded, still feared, and still ignored by many parents and professionals. It is an unknown territory where few wish to travel or explore.

Authors Karin Melber Schwier and Dave Hingsburger have done more than write a book. They have provided a comprehensive guide for parents into this complex area of life. Parents, significant others, and people with disabilities are introduced as "your guides" through the book. These guides share vignettes from their lives that are sometimes charming, sometimes humorous, and sometimes highly emotional.

The authors define sexuality as "the whole person: your thoughts, feelings, attitudes, and behavior towards yourself and others. Learning how, when, where, and with whom to interact and express our sexuality as a male or female is very important to our well being and to how well we will be welcomed and accepted by our community." In this context, the authors deal with many pieces of the puzzle that come together encouraging the development of a strong and healthy sexuality. Responsibility, self-esteem, expectations, relationships, independence, and dreams are explored throughout the book in a respectful manner. In doing so the authors present a natural, positive connection about sexuality that exists in everyone’s life. The authors point to similarities of desires, needs, and feelings of those with and without disabilities. They continually emphasize the importance of teaching people with disabilities about themselves and their feelings and that it is never too late for this education to begin.

Some of the topics in the book may be difficult for parents to read. However the authors have done a good job of presenting them in a sensitive, interesting, and thought-provoking manner. Candid comments for "your guides" as well as questions-and-answer sections in each chapter provide tangible, real-life examples that makes edu-
Sexuality: Your Sons and Daughters with Intellectual Disabilities

Continued from page 14

cating your family and child easier. This book serves as a much-needed blueprint for those questions and unpredictable moments all parents dread regarding sexuality giving us the direction we need to encourage healthy sexuality and a strong sense of self and confidence in our children.

For me, this book is a wonderfully positive, straightforward teaching tool that all parents will benefit from reading wherever they are in the journey of parenthood. It is definitely going on my personal “Top Ten List” of parenting books.

Cheryl Ward is the mother of two teenagers, the oldest, her daughter, has Down syndrome. She is the Education Service Coordinator at the Endependence Center (a Center for Independent Living) and the editor of the Tidewater Down Syndrome Association’s newsletter, Down Right Active. Cheryl and her family reside in Virginia Beach, Virginia.

Addition to “Healthy Lifestyles in Adults with Down Syndrome: A Survey”

In the last issue of Disability Solutions, Volume 4, Issue 4, we neglected to include the references for the article, “Healthy Lifestyles in Adults with Down Syndrome: A Survey.” For those wishing to investigate past studies related to the development of the article, they are listed below. Thank you for your patience. –JEGM

References

Sexuality Education: Building on the Foundation of Healthy Attitudes

by Terri Couwenhoven, MS

The first installment of this two-part series explained the importance of parents as primary sexuality educators. When sexuality concepts are taught early, they provide a foundation for helping your child move toward a sexually healthy adulthood. The article included strategies for parents, as teachers, to introduce key concepts over time. As our children with Down syndrome grow and develop, it is important to continue reinforcing earlier learning, while adding new information and concepts. As with all children, schools, churches, and other agencies will begin playing a larger role in augmenting sexual learning.

Building on the Foundation: The Growing Years

When your child is around 8 or 9 years old (a bit later for boys) they enter a phase I call “the growing years.” This rapid growth phase, typically referred to as puberty, marks the beginning of adolescence. It is a time that includes significant physical and emotional changes and presents challenges for all children, including those with Down syndrome.

For many families this stage is a “whack-over-the-head” reminder that their child with a disability will develop and mature just like everyone else. It is also be an opportunity to evaluate and assess where your child is regarding sexual learning. If you are just beginning to understand your tasks as your child’s primary sexuality educator and have not begun to formally work on the concepts and issues I discussed in the first article, don’t be hard on yourself. Instead use these growing years as a time to introduce these concepts and help your child feel good about who they are as a sexual person. If you’ve already introduced those foundational concepts, keep in mind earlier information will likely need considerable repetition.

Continued on page 3
from the editor

Disability Solutions is published at no cost to readers four times yearly by The Enoch-Gelbard Foundation, a nonprofit, independent, private foundation. If you would like to stop receiving this publication, please write to the publication address.

Readers are welcome to submit articles, reviews, letters to the editor, or photographs to the publication address. Please include your name, address, e-mail, and phone number with your submission. It is helpful if submissions are sent on disk or by e-mail in MS Word or another PC compatible format. If you cannot, please send submissions typed double-spaced. All submissions will be reviewed and edited for content and style.

No contribution or subscription fee is required to receive Disability Solutions. If you would like to help with the cost, you may send a tax deductible contribution to The Enoch-Gelbard Foundation at the publication address.

A goal of The Enoch-Gelbard Foundation and Disability Solutions is to make information widely available, free-of-charge to families, and professionals. The Foundation supports sharing information in the public domain, especially for families. You can download back issues of Disability Solutions from our website (see above) or request a printed copy at a cost of $2.50 while supplies last.

Reprint Policy

1. If you would like to reprint material from Disability Solutions at no cost to others, you do not need to request permission. When you do reprint material, please include the author’s name and list Disability Solutions as the source. When possible, it would be nice to see a copy of the article reprinted or the URL of the web page where it is located.

2. If you would like to reprint material from Disability Solutions in a book, newsletter, electronic, or any other format for which you may receive any payment, permission is required.

Please send requests for permission to the publication address.

Opinions and information published in Disability Solutions are not necessarily those of The Enoch-Gelbard Foundation.

Copyright © 2001, Disability Solutions.
Continued from page 1
and reinforcement as your child attempts to apply skills in new and different situations. Regardless of what sexual learning has occurred, new topics related to puberty and relationships will arise. This article addresses the topics and concerns that go beyond the foundational concepts to sexual learning.

Understanding Puberty

When it comes to physical sexual development in children, there are few differences between children with and without developmental disabilities. In other words, an eleven or twelve year-old with Down syndrome will experience the same physical signs of maturation such as breast development, pubic hair, body odor, at around the same time as other children. Consequently, targeted teaching and learning about puberty should begin just before puberty around the same time other children begin to learn about changes. For girls this usually occurs around age 10 and for boys around age 11 or 12.

Although inclusive classroom settings may provide a teachable moment, I encourage parents to advocate for additional programming adapted for their child who has a cognitive disability. In the inclusive classroom, it is common for a great deal of information to be covered in shorter periods of time using more sophisticated teaching materials. For pre-adolescents who already understand some of the basic concepts of puberty, it may be an opportunity for reinforcing previous learning. For children with cognitive disabilities, often the most relevant issues such as grooming and hygiene and appropriate behavior, are ignored completely or buried in a wealth of less relevant material. The topic of puberty was introduced at my daughter’s elementary school in fourth grade within a guidance class led by the school counselor. Since my daughter and I had had some initial conversations about what puberty meant and the changes that would happen to her, she joined the rest of her female classmates in watching a video that I had previewed previously. When I asked her about the movie, it was apparent she was so focused on the socialization of the characters (“two girls who giggled a lot”) that she missed key puberty information that was presented.

Puberty education for children with cognitive disabilities should focus on body changes, hygiene and grooming, awareness of sexual feelings, rules for public and private behavior, privacy for self and others, body ownership, and boundaries for self and others. It is also helpful to incorporate problem-solving approaches into puberty education. For example, a brainstorming session with males regarding what to do when spontaneous erections occur at inopportune moments helps to prepare them for those situations. Similarly in a female puberty program, I spend time towards the end of the series working on common problems such as what to do when your period starts and you do not have supplies. Together we discuss how those problems can be resolved.

Hygiene and Grooming

Puberty is a time when extra instruction about hygiene and grooming are needed to help our children achieve social acceptance. Hygiene is more related to cleanliness while grooming captures the rest of the details that relate to looking good: good haircuts, well manicured nails, teeth brushing and flossing, shaving, etc. For most children, disabled or not, a renewed interest in how they appear to others is normal. I encourage parents to use cultivate this stage to help their child develop good habits.

Teaching hygiene skills for children with Down syndrome usually means helping them understand steps in bathing. Learning to be independent with routine hygiene practices is our goal, but getting there will take time. As parents we forget how complicated hygiene can be. Many parents have found teaching to be more successful if they break tasks into smaller steps. For

Continued on page 4
example, the showering process alone can involve learning how to adjust water temperature, shampoo hair, rinse hair, wash the upper body, wash the lower body, rinse the body, etc. Teaching one step at a time, your child is more likely to be successful. My favorite resource for teaching the steps in showering is the First Impressions series published by James Stanfield company (see page X). I routinely use this video in my puberty programs. The video includes exaggerated comparisons of good vs. bad hygiene and the potential responses from others, which is something our children don’t often see. Although it may be cost prohibitive for most families, your local parent organization may be able to purchase a copy for their lending library so families can check it out. School districts also have budgets to supplement curricula being introduced in school.

Potential Problems with Hygiene & Grooming

Lack of interest in maintaining hygiene and grooming can be a problem for some families. If your child is resistant to hygiene rituals on a regular basis, look for ways to use incentives or methods that will reduce your child’s resistance. You know your child best. Discovering what will work best to keep them motivated to be well-groomed may take some creative thinking. For example, if there is significant resistance to showering at the end of the day (when fatigue and crankiness is often at its peak), morning showers may be less troublesome. Consider including positive reinforcement strategies as a component of completing hygiene routines. It is important to remember to gradually reduce the use of reinforcers as your child gains independence. The reward for showering, for example, may include watching a video, alone time, or other things your child likes to do before going to bed.

Be mindful of barriers that may be preventing your child’s progress. Our daughter had a difficult time with the shampoo rinsing portion of the shower which resulted in an unsightly “flake” problem and unclean-looking hair. Later we discovered she was spending as little time as possible directly under the showerhead. She explained that the water “hurt” (she did not like the high pressure shower stream). Adjusting the showerhead solved the problem. Another time I switched shampoo brands (and forgot to tell her). During her next few showers she became confused about which bottles were for what. She mistakenly used lotion for soap, soap for shampoo, and so on. Needless to say, she’d come out of the shower less clean than when she went in. We eventually purchased a shower bucket specifically for her hygiene and grooming stuff. This prevented future confusion.

Remember that taking care of our bodies is a big task and will require gentle persistence over time much like other things we try to teach our children. Other tips to consider include:

- Allow your child to become an active participant in choosing and selecting hygiene products. There are many “cool” products out there. Let them choose which ones they like best and they will be more likely to use them.
- Keep things simple- For example shower supplies should include a bar of soap (for people with Down syndrome a moisturized soap such as Dove or Lever is best) and shampoo.
- Teach hygiene/grooming in small steps. Work on one step at a time until your child masters them. Then move on to the next step.
- Praise and positively reinforce good hygiene and independence with hygiene as a normal part of growing up.
- Pay attention to clothing, hairstyles, and fashion trends you see on your child’s peers if your child doesn’t notice. If they do notice these trends, take them shopping!
- Introduce them to grooming routines that are relaxing, pleasurable, and appropriately social—good haircut, manicures, pedicures, facials, makeover parties lead by experienced make up artists, etc.
Social Skills

Part one of this series covered the importance of modeling and teaching social skills (manners, etc.) at early ages. As your child develops, building and expanding their repertoire of social skills requires ongoing coaching. When it comes to teaching social skills, most experts agree that individuals with cognitive impairments need individualized (based on unique strengths and weaknesses of the individual), targeted (focused on specific behavioral goals) instruction over time in a variety of settings. This means we can’t assume that an inclusive environment automatically means our child’s social skills will develop automatically. As parents we need to contrive social situations in concrete ways to allow for safe practice fairly often.

One of the challenges for parents is being aware of which social skills to work on with their teenager. Some examples of basic social skills include:

- Using appropriate greetings such as hello, goodbye, and knowing when to shake hands or offer a hug.
- Making eye contact when speaking or listening to another person.
- Using manners appropriately such as saying “thank you,” “I’m sorry,” or “excuse me.”
- Offering sympathy or support to others who are feeling badly.

Keep in mind the early teen years are also a time when our children begin to show an interest in developing relationships. This requires an entirely different set of social skills. Some examples of social skills needed for dating and relationship development include:

- Introducing yourself and others to someone,
- Initiating conversations with others,
- Arranging or accepting a date with a friend,
- Active listening,
- Understanding emotions, both verbal and non-verbal,
- Finding similarities to others,
- Giving and receiving compliments, and
- Compromising.

Assertiveness as a Social Skill

For most children, it is natural for parents to allow them to become more verbal about expressing their choices and decisions as they get older. Being able to express needs, desires, choices, and opinions is a set of skills we need in order to be independent and develop and sustain healthy relationships. For example, the skills needed to meet new people, extend social invitations, ask, or accept a proposal all require assertiveness.

Assertiveness is also important when we discuss self-protection and exploitation prevention. Individuals with developmental disabilities who are positively reinforced for being compliant, passive, and obedient have difficulties with this skill. As parents, we need to respect, and in appropriate situations, encourage non-compliance when it keeps them safe. Avoid using statements like “listen to...” or “do what they say” statements.

The majority of sexual abuse among people with developmental disabilities is perpetuated by someone the victim knows and trusts. Often we lull our children into trusting others’ opinions about what is best for them rather than allowing them to choose. While not easily undone, when people are given instruction, support, and opportunities to practice assertiveness, tremendous growth can be seen. Allowing our children to assert themselves with friends, family, and others authority figures early on is a practical experience and something that can be done on a regular basis.

Recently, my daughter and I planned to meet some friends for lunch at McDonald’s. Following their meal, Anna and her friend decided they each wanted an ice cream for dessert. I gave Anna a dollar, my friend did the same with her daughter. The girls went up to the counter to order and a short time later, her friend returned with a McFlurry and Anna, head hanging and frustrated, returned with nothing. Her friend had ordered first and when she realized she needed more money, she asked for or took (we’re still not sure) Anna’s dollar. I am still amazed at what an impact this situation had on Anna (she still

Continued on page 6
Building on the Foundation: The Growing Years

Continued from page 5
talks about it). Often life experiences such as these become significant and memorable teaching tools for our children. Don’t be afraid to use them, but do frame them in a proactive and positive manner. David Hingsburger also reminds us in his book, Just Say Know: Understand and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities, “unless we can say no to small things we won’t be able to say no to big things.”

Relationships

Helping your child understand relationships and the implications for how those relationships affect the way we touch, talk and behave with each other can be an abstract concept but is a critical component of sexuality education. Most curricula designed for individuals with developmental disabilities break down types of relationships into the following categories:

☆ Self: It is difficult for most of us to develop healthy relationships with others unless we first have a solid understanding of who we are and what we’re about and feel good about who we are. Being able to have a relationship with our self is an important foundation for future relationship development.

☆ Family, Friends, Community/Professional Helpers, Acquaintances/Strangers.

There is more to relationships, however, than being able to categorize them. Therefore, instruction around relationships should also include:

・ The roles these relationships play in our lives,
・ Societal rules for behavior such as talk and touch boundaries, within these different relationships, and
・ An explanation of the consequences when societal rules are not followed.

One of the more popular teaching tools for helping individuals with cognitive disabilities learn and understand these concepts is the Circles system (see page X). This resource visually presents levels of relationships within concentric, colored circles. The inner circle representing the relationship we have with our self (the most important relationship), with additional circles moving away from the inner circle. The basic concept of the Circles program is the closer the circle is to you, the more intimate the relationship. Understanding the rules that apply to each circle helps clarify appropriate talk, touch, and behavior for various people. This understanding helps people gain control over their relationships, their bodies, and feelings. Other relationship topics could be include:

・ Selecting a partner;
・ The cycle of relationships: how they begin, grow and change; and
・ The characteristics of healthy vs. unhealthy relationships.

By helping our children understand different relationships and appropriate behavior within relationships, they will recognize inappropriate behavior more easily. For example, when they encounter a person who is invading their space, giving them gifts, or acting like a best buddy when they only just met (all examples of behavior that exploiters use to gain trust) they will recognize the inappropriateness of these behaviors more readily. Similarly, if they have been given information about rules related to touching private parts or that being hurt (physically, verbally, or sexually) is not a part of a healthy relationship, they can more easily evaluate their relationships and get help.

When teaching relationships and appropriate behavior within relationships, it is important to look holistically at the world of the individual who may be having difficulty with these issues. A person who is isolated from others is more likely to latch onto the first person who pays attention to them regardless of the appropriateness or quality of the relationship. The bottom line is when individuals with developmental disabilities do not have opportunities to develop relationships with others. Their ability to discriminate between appropriate and inappropriate relationships is diminished, making them more vulnerable to exploitation.

Reciprocity within Relationships

Within many families, the person with Down syndrome or other disability grows up experiencing...
Building on the Foundation: The Growing Years

an elevated sense of “specialness.” This phenomenon arises from repeated opportunities for being the center of attention within social contexts and often, over time, can result in an unappealing self-centeredness that makes it more difficult to develop meaningful, or any, relationships. Individuals in these situations have a more difficult time understanding the concept of give and take that is necessary within healthy relationships. A friend of mine, who supports individuals with developmental disabilities living in the community, worked with a woman who had difficulty with social skills and the concept of mutuality. She often invited her friend over so she could model appropriate etiquette, such as offering a soda or snack and occasionally preparing a formal dinner. When she visited her client’s house, these gestures were not usually reciprocated. On one occasion she attempted to give her client a prompt by asking if she could have a soda. Her client’s response was “They’re in the pantry and that’ll be 50 cents.”

Our children need to understand at early ages the importance of mutuality and interdependence. The world can’t and shouldn’t always revolve around them. There will be times when they’ll need to do more giving than receiving such as in jobs and relationships. Many adults I know with disabilities would love more opportunities to be a part of the community giving of themselves in purposeful ways. Facilitating this can increase their understanding of the meaning of reciprocity, help them feel better about themselves, and increase meaningful relationships in their lives.

Exploitation Prevention

When I lead education sessions for parents who have children with special needs, one of their most pressing concerns is how to keep them safe. As much as we’d like to believe, as parents, we are able to protect our children from danger, exploitation, and other unfortunate occurrences the truth is it’s impossible.

Not long ago I received a phone call from a distressed mother who had attended a workshop I had done some ten years earlier. Her son had been fairly young at the time and she believed, like most of us do, there was plenty of time. She called me because she discovered her son, now a teenager, had been sexually exploited by his peer who lived next door. What was disturbing, to both of us, was not that the exploitation had been perpetuated by his good friend, but that it had been going on for quite some time. Her son never told her. She was able to pick up on a subtle non-verbal cue in the car one day that made her think she needed to figure out what was going on. Later she told me she didn’t think anything could happen to her son since they lived in the country where her son was fairly isolated from others.

Those of us who work in the field of sexuality understand that people at the greatest risk of exploitation are those individuals who are insulated, protected or sheltered from what can happen. My philosophy and response to parental fears about exploitation never waivers: the best way to help your child avoid exploitation is to give them the tools they need to be empowered and educated. Information and language are powerful tools and one of my primary motivations for writing this article.

Be leery, however, of sexuality programs initiated for the sole purpose of keeping people safe rather than comprehensively addressing a wide variety of issues that contribute to healthy sexual adulthood. A good sexuality program can and should do both. For example, teaching assertiveness skills, boundaries and appropriate behavior, sexual language for body parts, and characteristics of healthy and unhealthy relationships help prevent exploitation, but also make your child feel good about who they are and that goes a long way in making them less vulnerable to exploitation. Other important skills and information include:

- Understanding common tactics used by abusers
- Discussing laws and societal rules regarding inappropriate touching such as child/adult touching, boss/employee touching.
- Developing basic safety skills such as say no, get away, buddy systems, and so on.
- Reporting skills. This includes identifying at least three key people who they can tell and emphasizing persistence when they are not believed.

Continued on page 8
Adolescence can be a difficult time for all children. Teens with disabilities are no exception. Not only are they developing physically, but psychosocially as well. During this phase all teens struggle as they try to understand who they are and what they can become (identity). They’re attempting to understand, in their own way, how to get along with others (relationships and intimacy) and learning how to become more independent. For the average teen, these are difficult issues to sort through. For teens with Down syndrome, extensive discussions and coaching will be necessary.

Independence

One aspect of psychosocial development for all pre-adolescents is an evolving separation from parents and increased need for independence and autonomy. Understanding this a normal part of growing up should be our cue for starting to create or cultivate opportunities that encourage growth and independence.

Our twelve-year-old daughter has recently started to indirectly express her need and desire to be independent. One day Anna decided to mail a stack of letters that she noticed on our table. Without telling any of us, she picked them up and mailed them at a mailbox a few blocks from our house even though most of the letters had no stamps or return labels. We positively reinforced her helpfulness, emphasized the fact that she should tell someone when she is leaving and now have her put the stamps and return labels on the envelopes.

A few days later, my husband found Anna giving herself an albuterol inhaler treatment. This required a little talk about medicines, the consequences of overdosing, label reading, and why adult assistance is a good idea. We did begin having her keep track of the time between doses so she could remind us when she was due.

I was very proud of her a few weeks ago when she just decided to call me on the car phone to let me know she was home from school. We have always kept our phone numbers near the phone for this purpose. She took the initiative to call me, rather than waiting for me to call her.

All of these incidences were emerging attempts at demonstrating her need to be independent. Managing and organizing homework, planning social activities, delegating household chores, or allowing incremental “home alone” time, are other examples of ways to help encourage and reinforce independence.

Understanding Their Disability

Exploring the issue of identity for our children often means coming to grips with their disability. We began talking about Down syndrome with Anna at a very young age. I’m certain she didn’t completely understand it, however, until her first year in middle school. For the first time since Kindergarten, she had another student (new to the district) with Down syndrome in her homeroom. Anna is a visual learner and I’m convinced that by observing her classmate with Down syndrome, she more clearly understood what it meant for her. I was unaware of her internal identity struggles until one October evening when we were doing homework. She was having some difficulty with an assignment when she suddenly put her pencil down and asked, “Mom, do I have Down syndrome?” (she often checks in with me on things she already knows—just to make sure). “Yes, you have Down syndrome”, I responded. She sighed, then shrugged, with frustration, hung her head in her hands and said, “I just want to be a regular kid.”
wasn’t until then that she began to see with accuracy her differences. As much as I wanted to paint a rosy picture, I knew deep down we needed to discuss her limitations. She saw and understood them on a daily basis, and I needed to be honest. We talked about what it meant to have Down syndrome. I told her it would often take her longer to learn new things and that sometimes people had a harder time understanding her. Then we discussed ways she was like everyone else. We talked about her future, about having a job and living on her own. Parents who can speak honestly with their children about their disability model acceptance that is helpful in fostering a clearer sense of self for the child. How does this relate to sexuality? Feeling okay about every aspect of who we are, is a critical foundation for healthy self esteem. Our children must feel good about who they are before they can begin to develop healthy relationships with others.

Sexual Orientation

Adolescence is a time when an understanding of sexual orientation begins to materialize. Although there is very little literature on the incidence of homosexuality and people with developmental disabilities, we need to assume it mirrors the general population. Because people with cognitive disabilities often experience limited access to partners and choices in living arrangements, determining their sexual orientation can be more complicated that it is for the nondisabled. For example, among people with developmental disabilities who live in gender-segregated homes often same-sex encounters are exhibited (much like behavior that occurs in prisons). In these situations residents often have fewer opportunities to choose with whom they will form relationships. In the field of sexuality, this phenomenon is referred to as situational homosexuality. When these same residents are allowed heterosexual contact, often they return to heterosexual behavior.

Just like non-disabled gays, people with developmental disabilities who are gay risk ridicule and prejudice once they come out. A few years ago I was asked by a county case worker to provide safe-sex information to one of her clients- a young gay women with a developmental disability. Although she was interested in the information, it became clear that her real need was for support and acceptance. Her efforts at seeking out help from a non-supportive staff person had resulted in more rigid social restrictions (preventing her from seeing her partner), alienation from family, and isolation from roommates. Other important points to remember regarding sexual orientation:

- One same-sex encounter, crush, dream does not necessarily mean your child is gay or lesbian. Occasional homosexual experiences are a fairly common phenomenon among teens and not a good predictor of sexual orientation.
- Although many individuals who are homosexual report feeling different early in life, acceptance of identity usually occurs in adulthood.
- Thoughts and fantasies are a better indicator of sexual orientation than behavior.

If you suspect you child may be gay, they will need information and support just like everyone else. Research national and community resources that exist and be prepared to help them access the materials they may need to accept and feel good about who they are.

Dating and Relationship Development

Beyond the relationship concepts that are taught, I’ve listed other issues within the realm of relationships that repeatedly surface for the clients I teach and/or with parents who have teens and adults with developmental disabilities. I don’t have magic answers on some of these issues but I do believe that becoming aware of the issues is the first step in figuring out ways to address them.

Access to partners

Some time ago during a visit to our clinic, a mother approached us regarding her 19-year-old son with Down syndrome. She was concerned about his recent and developing interest (and from what I could gather it was mutual) in a girl

Continued on page 10
from his cognitive disabilities class at his school. The mother came to us wanting some ideas on how she could “nip-it-in-the-bud” (the relationship) before it developed into something serious!! This story still haunts me for a number of reasons. Let’s face it, loneliness and isolation are common problems among people with disabilities. Within the programs that I do, participants with developmental disabilities often share their frustration over the difficulties in finding a friend, companion, or partner. Limited transportation, lack of privacy, fewer opportunities for socialization, and often societal stereotypes and pejorative attitudes about people with disabilities and sexuality make finding a partner, getting together and developing a relationship much more difficult. The desire to have a meaningful relationship with a partner is a need we all have. Becoming another obstacle for our children is unacceptable. Instead, we can facilitate this process by:

- Ensuring our children are socially active particularly in early and late adolescence (and throughout life). Participation in clubs, hobbies, recreation and leisure activities increases their chances of finding meaningful companionship and developing friendships that could potentially result in long term relationships.
- Listening to what our children are telling us. Too often we ignore, subtly discourage, or shatter hopes and opportunities for connecting with others because of issues we have as parents.
- Continuing to teach and reinforce social skills that are needed as they arise.

Many parents experience discomfort when their teen or young adult expresses their desire to develop a sexual relationship with a non-disabled peer. As younger generations of children are growing up in inclusive settings, this phenomenon will understandably become more prevalent. We need to remember that people with developmental disabilities see the same role models as we do in the media and in life. Not since Chris Burke’s television role in Life Goes On have there been models for young adults with Down syndrome. Negative stereotypes and attitudes about people with developmental disabilities are still prevalent. As a result, our children often view finding and dating a “normal” person as a more appealing and acceptable option.

Privacy

At a sexuality conference a few years ago, I was having lunch with a wonderful group of sex educators who specialized in working with people who have developmental disabilities. One of my friends was sharing his story about how he routinely challenged parents of children with special needs to think about how they will handle consensual sexual activity when the time comes. For the non-disabled, private locations for sexual activity are plentiful— a college dorm room, an apartment, a tent. For people with disabilities who rarely drive, and are often living at home well into adulthood, finding a private place to be affectionate is more challenging.

I tell this story because I have been called to “deal with” couples or clients who have been discovered displaying affection or participating in sexual activities in public places. After speaking with them it becomes apparent that group home policy, staff and parental attitudes, etc. prevent them from being together in private places that would be more appropriate. We need to remember that when limits or restrictions are placed on private sexual expression, sexual activity often moves into the public arena.

Consent

One of the dilemmas frequently facing parents and providers is balancing the need to both protect and support individuals with developmental disabilities in their right to make sexual decisions. Often the key factor in determining this is whether the individual has the capacity to consent to sexual activity. Factors that alter or contribute to the confusion regarding a person’s ability to legally give consent include:

- a lack of information or knowledge about sexuality such as boundaries concepts, information on how to prevent themselves from consequences of sexual activity, and
- the ability to make decisions voluntarily and free from coercion.
Sexuality Education in Schools and Community

By the time your child approaches adolescence, schools should be providing learning opportunities that augment and reinforce learning and understanding sexuality issues. However, here’s a warning. Although our country has made progress in accepting the fact that non-disabled adolescents are sexual and therefore need quality sexuality education, when it comes to providing sexuality education for teens with developmental disabilities, we still have a long way to go.

Educating people with Down syndrome within inclusive classrooms is occurring more frequently than it has in the past. Sexuality education within the regular curricula, however, looks different than the training typically provided for individuals with developmental disabilities. Some benefits of involving your adolescent in programming specifically geared toward people with cognitive disabilities include:

- smaller groups of students,
- smaller amounts of information presented per session,
- improved content relevancy focusing on common issues and problems,
- use of specialized, more concrete teaching materials,
- increased opportunities for repetition and reinforcement, and
- safer “practice” settings for reviewing and applying skills among peers.

Even if your child’s school offers instruction geared towards the needs of individuals with cognitive disabilities, there can be wide variability in the quality of programming. Community attitudes and beliefs, skill and comfort level of the instructor, resource allocation (funding), and parental support are factors that typically affect program quality. Here are some questions and background information that may be helpful as you attempt to evaluate and advocate for comprehensive programming:

What topics are covered?

Concepts and information taught within a program should include: Parts of the Body, Maturation and Body Changes, Personal Care (Hygiene, feminine care, medical exams, etc), Social Etiquette (grooming, social skills), Relationships, Exploitation Prevention, Dating/Relationship Development, Sexual Expression within Relationships, Pregnancy Prevention (Birth Control), Sexually Transmitted Diseases and their prevention, Rights and Responsibilities of Sexual Behavior.

Who Teaches the Program?

I have met teachers who are comfortable working with people who have developmental disabilities but not at all comfortable with sexuality issues. This scenario often results in incomplete, “problem-focused” programming (information designed to fix a problem rather than cultivate sexuality) that includes “safe” and non-controversial sexuality topics (i.e exploitation prevention, body parts). In other situations, sexuality educators can be skilled and comfortable teaching sexuality topics, but have little or no experience working with or teaching people with developmental disabilities. The consequence is programming that is too sophisticated and complex, decreasing relevancy and comprehension for the students. Involving a certified sexuality educator who has experience working with people who have developmental disabilities is ideal.

What values are inherent within the program?

Usually when referring to values within curricula, it is in reference to universal values we all agree are important. Examples of these values include:

- Sexuality is a natural and healthy part of who we are.
- All of us are sexual.
- Sexual activity comes with responsibilities.
- Exploiting or hurting others is wrong.

How is learning evaluated?

Student learning associated with sexuality programming can be evaluated through paper and pencil testing (labeling, selecting appropriate
responses, picture selection), board games, oral tests, or behavioral testing (role play, observation of skills within contexts outside the classroom, In situ assessment).

Critical times for programming within the school setting include job-training programs. If your child is transitioning from school to community, sexuality education, in some form, should be a component of the curriculum. If your child is no longer in school, advocate for sexuality programming within other contexts. Sheltered workshops, disability agency job training programs, clubs, or other groups your child belongs to can effectively integrate sexuality information into existing programs. Often the programs I am asked to do are started by groups of parents or professionals who are simply listening and responding to the needs of individuals with disabilities.

When Sexuality Education Isn’t Enough

Participating in the best sexuality program doesn’t guarantee sexual problems will be resolved. Usually it’s a good beginning and first step in helping people with disabilities gain a better understanding of who they are and how they appropriately interact with others. Sometimes, despite our best efforts, things go array. It’s important to remember that sexual problems often carry extra baggage and discomfort resulting in escalated reactions from parents and others working with your child. Handling and resolving problem behaviors will require collaborative work and communication between all people supporting your child. Help and support from trained counselors or therapists who are trained in the therapeutic process of dealing with feelings may be necessary if the individual’s problem behavior is creating dysfunction or unpleasant feelings to surface. These feelings may surface as a result of normal development or past traumatic experiences such as sexual abuse. A trained counselor can help the individual sort through feelings and develop strategies for addressing the problem behavior. For many families, finding a qualified counselor can be a difficult. Although most communities have access to counselors, finding someone who is trained in dealing with sexuality issues and comfortable working with an individual who has limited verbal abilities and/or cognitive limitations is often a challenge. You may be able to get help by contacting the following organizations.

Local Disability Organizations

Most agencies supporting individuals with developmental disabilities (ARC, UCP) by now recognize their needs and rights related to sexuality. Often these agencies have compiled lists of resources for counseling or are aware of emerging experts in this area. With increasing frequency, communities are offering support groups that address the unique needs of people with cognitive disabilities.

Planned Parenthood Organizations

Although not all Planned Parenthood agencies around the country have staff who are trained or experienced in working with individuals with developmental disabilities, more often than not, they have a good level of comfort addressing sexuality issues in general. Many times these organizations are the first to initiate services for specialized populations.

AASECT Counselors and Therapists

AASECT (American Association of Sex Educators, Counselors, and Therapists) is the only organization devoted to training and certification of professionals in order to promote sexual health. AASECT Certified counselors or therapists have extensive training in all aspects of sexuality and are available in most states. Few, however specialize in working with individuals with developmental disabilities. If you are fortunate enough to have one of these resources in your community, it’s likely the above agencies know who they are and how they can be reached.

Conclusion

This two-part series was designed to identify a list of key concepts and issues that, when addressed early in life, can provide a good foundation for the development of healthy sexual attitudes from which to build as your child matures. The concepts and issues identified in this series are by no means comprehensive, but meant to
give you a good start towards the problems that we so often see after years of sexual repression and denial.

Teaching all of the concepts listed may never happen for some families. For children with more severe cognitive impairments there may be less emphasis on social skills and more time spent on helping your child feel good about who they are. What’s most important is that you recognize your child has sexual and informational needs like everyone else. Good luck on your journey!

References:

Terri Couwenhoven, MS, is the mother of two daughters, one of whom has Down syndrome. She is an AASECT certified sexuality education consultant and Clinic Coordinator for the Down Syndrome Clinic of Wisconsin. You can contact her by e-mail: tcouwen@execpc.com or by US Mail: TC Services, 209 N. Spring Street, Port Washington, WI 53074.

Sexuality Resources for Teaching & Learning

The following is a listing of my favorite resources for teaching about sexuality. Most of these can be purchased through any major bookstore or at amazon.com. If not, the source where it can be purchased from is listed after the description.

**Foundational Sexuality Concepts**

A story about two young children discovering their body parts while bathing together. Useful for helping children understand differences between boy and girl bodies and identifying correct names for private body parts.

A beautiful yet simple book that encourages appreciation of uniqueness and includes empowering messages about the body, feelings, boundary awareness, touch, and feeling safe. Comes with a Leader’s Guide (useful for parents as well) supplemental activities that affirm the concepts above. Both the Guide and children’s book can be purchased through Free Spirit Publishing at www.freespirit.com for about $30.00.

A humorous book about feelings. A fun spin diagram in the back allows children to change the look of the face based on feelings (sad, happy, excited, cranky, angry).

**Face Your Feelings**, Published by Child’s Work/Child’s Play. www.childwork.com 1-800-962-1141.
A book and card deck set that help children understand the importance of expressing and understanding feelings. The book and card deck show 52 pictures of children, teens, adults and seniors expressing 12 basic feelings. Designed for ages 4 and up.

A nice, easy-to-read story book for young children that addresses how boys and girls are different (come to find out the only way they are different is physically). The book addresses societal rules related to talking, looking, touching, and being touched and reproduction.

Puberty Resources for Pre-Adolescents

Changes in You by Peggy Siegel. Published by Family Life Education Associates, P.O. Box 7466, Richmond, VA 23221. 804/262-0531. $10.45.

The only book written specifically for girls and boys with cognitive disabilities, this book uses beautiful illustrations and straightforward language to explain the physical, emotional, and social changes of puberty. Separate book for boys and girls.


This American Girl “head-to-toe” advice book addresses female puberty changes, hygiene issues, self esteem, fitness, sleep and emotions. Lots of color pictures and easier text makes it fun reading for girls with lower reading levels. Includes empowering messages about the body.


A more advanced book for females that covers “changes you can see” and “changes you can’t see” but also includes information about tampon use, first pelvic exams, and how to handle common problems. Available through www.newmooncatalog.com.


A humorous approach to male and female puberty. Mostly animated drawings with a few realistic ones thrown in.


A comprehensive book that uses color illustrations to address puberty (male and female), reproduction, birth, sexual orientation, decision making, and staying healthy.


A workbook companion piece entitled My Body, My Self for Boys can be purchased separately and includes reinforcement games, checklists, and quizzes. A little busy, but can give parents ideas for reinforcement activities.


A workbook companion piece entitled My Body, My Self for Girls can be purchased separately and includes reinforcement games, checklists, and quizzes. A little busy, but can give parents ideas for reinforcement activities.

Hygiene and Grooming

First Impressions Can Make a Difference, James Stanfield Publishing Company. www.stanfield.com or call for catalog 1-800-421-6543. Approximately $189 for each video series.

A four-module video series that addresses hygiene, grooming, dress, and attitude using humor and exaggeration. Modules are sold separately.

Comprehensive Sexuality Resources for Parents and/or Teachers

Being Sexual: An Illustrated Series on Sexuality and Relationships by Susan Ludwig and David Hingsburger. SIECCAN 850 Coxwell Avenue East York, Ontario M4C 5R1.

This series, designed for teens and adults, includes information on personal feelings, individual rights and societal expectations related to a variety of issues. Key concepts and information is translated into Blissymbols.

An excellent resource addressing sexual development issues across the life cycle from birth to adulthood. Parents, and their sons and daughters with developmental disabilities share helpful stories for parenting sexually healthy children. Many portions of the book speak specifically to people with Down syndrome and their parents.


A wonderful guide to help parents of children with an intellectual disability discuss sexuality with their children. Includes information on teaching social skills, talking to children about bodies and feelings, decisions, STDs and exploitation prevention. Lots of personal stories about families and personal experiences addressing tough issues. Can be ordered through the Roeher Institute at www.indie.ca/roeher/catalogue. This book is listed under the Education and Learning category.

**Special Education: Secondary Family Life and Sexual Health (FLASH)** by Jane Stangle. Family Planning Publications, Seattle-King County Department of Public Health. Suite 300 110 Prefontaine Avenue South, Seattle, WA 98104, 206-296-4672.

A great curriculum that can provide lessons on teaching relationships, public and private, relationships, communication, puberty, feelings, exploitation prevention and more.

**I Openers: Parents Ask Questions About Sexuality and Children with Developmental Disabilities** by David Hingsburger. Mariah Management. $15.00. 1-800-856-5007

A book full of common questions answered by one of the most well known and respected individuals in the field of sexuality and disability.


One of the most comprehensive slide series and script for teaching about sexuality. Part I focuses on the physiological and emotional aspects of being male or female. Part II emphasizes the moral, social and legal aspects of sexuality.

**Exploitation Prevention**


A wonderful resource for parents or professionals, this book provides straightforward information on how we contribute to making people with developmental disabilities more vulnerable to exploitation, signs and symptoms of abuse, and strategies for empowering people with developmental disabilities to protect themselves.


A great book for parents who want to do all they can to empower their children to be safe. Although the book does not specifically speak to children with developmental disabilities, some of the information is easily transferable. Addresses intuition, safety rules, and includes a section that specifically addresses children with autism.


A program designed for children with special needs ages 3-7 by experts who work with children with disabilities. The package includes pictures, anatomically correct dolls, and lessons.

**Masturbation**


A video and teaching program for adult males with developmental disabilities. A how-to video that models safe and appropriate masturbation.
Finger Tips: Teaching Women with Disabilities About Masturbation Through Understanding and Video by David Hingsburger and Sandra Haar. Published by Diverse City Press. www.diverse-city.com. $45.00.

A video and teaching program for adult females with developmental disabilities. A how-to video that models safe and appropriate masturbation.

Puberty


A great resource for mothers or fathers who want to brush up on facts as they prepare for discussions about menstruation. Includes some of the most current information available and emphasizes communication with discussion starter activities.


Ideal for professionals who are interested in setting up parent/child puberty workshops.


Laminated pictures with scripts on the back that can be used for teaching about the physical and emotional changes of male and female puberty. Comes with Teacher’s Guide and Changes in You books.


This training manual provides extensive background information, a video and instructional curriculum for teaching about menstrual hygiene with young women with severe developmental disabilities.

Relationships


A popular relationships training program that teaches relationship-building, social distance and exploitation prevention skills. Designed to be used with middle school through adulthood.

Relationship Series by National Institute for People with Disabilities. Published by Young Adult Institute (YAI) at (212) 273-6517.

A comprehensive videotape series that includes a friendship series (differences between strangers, acquaintances, and friends, becoming acquaintances or friends, and being a friend), boyfriend/girlfriend series (starting a special relationship, building a relationship I like, and having a good relationship), and sexuality series (enjoying your sexual life, working out problems in relationships, and sexual acts that are against the law).

Social Skills


A card game that creates plenty of real-life situations to practice and reinforce learning. The game addresses skill areas in compliments, social interaction, politeness, criticism, and social confrontation in the contexts of Social/Vocational, Social/Sexual, and so on.


A six-part video series that introduces middle school through adults to proper social behavior. Topics include: why manners are important, manners at home, at the table, in school, in public and when conversing with others.


By comparing observations to current theories of childhood friendship, the Debbie Staub helps us to understand the value of relationships between a “typical” child and one with moderate to severe disabilities. She also provides practical suggestions to help teachers and parents foster and maintain friendships in inclusive settings. This thought-provoking book provides important, real-life evidence about the merits of inclusion and can help guide educators and parents of all children into the future.
Sexuality Resources

ORGANIZATIONS/WEBSITES

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
800-433-5255
www.thearc.org

National Dissemination Center for Children with Disabilities (NICHCY)
PO Box 1492
Washington, DC 20013
800-695-0285
www.nichcy.org

Planned Parenthood Federation of America
810 Seventh Avenue
New York, NY 10019
800-230-7526
www.plannedparenthood.org

Sexuality Information and Education Council of the United States (SIECUS)
130 West 42nd Street, Suite 350
New York, NY 10036
212-819-9770
www.siecus.org

Disability Solutions:
Sexuality Education: Building a Foundation for Healthy Attitudes (Two-Part Series)
www.disabilitysolutions.org/pdf/4-5.pdf
www.disabilitysolutions.org/pdf/4-6.pdf

BOOKS

Braden, Marcia L. Fragile: Handle With Care, Understanding Fragile X Syndrome, 2000.
Contact The National Fragile X Foundation, 800-688-8765.
