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? Had she been 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.”

“Moommm, 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 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

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Sexuality Education: Making it Easier for You & Me

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. It is for me, anyway. 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.

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Take good care,
Joan Guthrie Medlen, Rd., LD
Editor
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.

Sexuality Education: Building a Foundation for Healthy Attitudes

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

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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.
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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

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repeated, supplemented, and reinforced 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.
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Use everyday teachable moments to reinforce foundational concepts. For example, if your child is dressing, remind him to 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.

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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 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 followed 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 non-discriminatory 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.

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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 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 handshakes, 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 feelings: “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
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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 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.

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References:

Sexuality: Your Sons and Daughters with Intellectual Disabilities


by Cheryl Ward

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 Melberg 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 educating 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 Independence 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.

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

Disability Solutions
A Resource for Families and Others Interested in Down Syndrome and Developmental Disabilities

Editor, Joan Guthrie Medlen, R.D., L.D.
Disability Solutions is published four times a year by Creating Solutions.
Creating Solutions is a project of The San Francisco Foundation Community Initiative Funds (TSFFCIF), a 501(c)3 public charity, our fiscal sponsor.

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TSFFCIF, Creating Solutions
ISSN: 1087-0520

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