

Disability Solutions

A Resource for Families and Others Interested in Down Syndrome and Related Disabilities

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Focus:

Sexuality Education

Part Two of a Two-Part Series

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

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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 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 and reinforcement as your child attempts to apply skills in new and different situations. Regardless of what sexual learning has occurred, new topics

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Sexuality Education:

Making it Easier for You & Me (part two)

In part one of this series on sexuality education Terri Couuwenhoven gave parents and professionals a framework for building a foundation of healthy attitudes for our children with Down syndrome. The foundation includes understanding sexual learning, proactive sexuality education, and describes key concepts that are important to introduce when children are young.

In this issue of *Disability Solutions*, Terri once again compassionately, yet proactively, takes us past the foundational concepts of childhood sexuality education and into the myriad topics faced by adolescents and adults with Down syndrome and related disabilities. Part two of this series, “Building on the Foundation: The Growing Years,” provides parents, professionals, support personnel, and friends an understanding not only of the unique hurdles our children face in this area, but how to advocate for appropriate sexuality education programs. In other words, you can use this issue of *Disability Solutions* to explain to staff at school, at a group home, at your child’s support group, or wherever this type of education is occurring, just what it is you would like to see in a sexuality or grooming and hygiene program.

Last, Terri has provided an extensive list of resources for the entire sexuality education series. She has previewed each resource and shares the strength of each one to assist you in making a decision.

I hope you will find this issue helpful when dealing with a difficult topic for most people. I, personally, found some good advice for my entire family.

Warmly,

Joan E. Guthrie Medlen, R.D., L.D.

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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, with or without disabilities, 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 involved 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 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

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(see page 14). 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 crabbiness 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 soap with moisturizer such as Dove is best) and shampoo.
- ◆ Teach hygiene and 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 such as a good haircut, manicures, pedicures, facials, makeover parties led by experienced make up artists, and so on.

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 automati-

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cally means our child's social skills will develop. 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 nonverbal,
- ◆ 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 other 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. 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 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 af-

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fect 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 oneself 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 16). This resource visually presents levels of relationships within concentric, colored circles. The inner circle represents the relationship we have with ourselves (the most important relationship), with additional circles moving away from the inner circle. The basic concept of the *Circles* program is that 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 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 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

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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.

Adolescence and Adulthood

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

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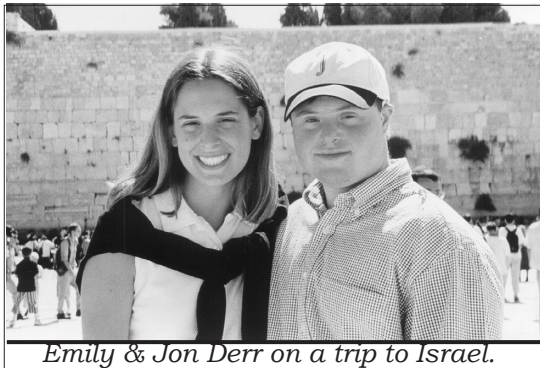
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and maturity and learning how to become more independent. For the average teen, these are difficult issues to sort through. For teens with Down syndrome, extensive discussions and coaching will be necessary.

Independence

One aspect of psychosocial development for all pre-adolescents is an evolving separation from parents and increased need for independence and autonomy. Understanding that 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



Emily & Jon Derr on a trip to Israel.

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 home-room. 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?”

“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.” It 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

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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 be aware of and open to the possibility. Because people with cognitive disabilities often experience limited access to partners and choices in living arrangements, determining their sexual orientation can be more complicated than 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 nondisabled 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 woman 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 les-

bian. 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 your child may be gay, she will need information and support just like everyone else. Research national and community resources that exist and be prepared to help your child access the materials needed to accept and feel good about who she is.

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 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 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 conduct, participants with developmental disabilities often share their frustration over the difficulties in finding a friend, companion, or partner. Limited transportation, lack of privacy, ~~few opportunities~~

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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. Allowing it to be 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

As children, with or without Down syndrome, approach adolescence, schools begin to provide learning opportunities that augment and reinforce what they have learned regarding sexuality issues. However, while we have made progress in accepting the fact that nondisabled adolescents are sexual and need quality sexuality education,

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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 including hygiene, feminine care, medical exams, and so on; Social Etiquette such as grooming and social skills; Relationships; Exploitation Prevention; Dating/Relationship Development; Sexual Expression within Relationships; Pregnancy Prevention (Birth Control); Sexually Transmitted Diseases and their prevention; and 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 (such as exploitation prevention and body parts). In other situations, sexuality educators are 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, which decreases the relevance and comprehension for 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 commu-

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Continued from page 11

nity, 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 conduct 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 awry. 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 counselors or therapists who are trained in the therapeutic process of dealing with feelings may be necessary if the individual's problem behavior is causing 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 is not easy. 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 recog-

nize their needs and rights related to sexuality. Often these agencies have 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. However, few 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 she is. What's most important is that you recognize

Building on the Foundation: The Growing Years

your child has sexual and informational needs like everyone else. Good luck on your journey!

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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

[Bellybuttons are Navels](#) by Mark Schoen. Published by Prometheus Books, 1990. ISBN: 087955857, \$19.00.

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.

[Just Because I Am: A Child's Book About Affirmation](#) by Lauren Murphy Payne. Published by Free Spirit Publishing, 1994. ISBN: 0915793601, \$8.95 (child's book), \$13.95 (instructor book).

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.

[Today I Feel Silly & Other Moods That Make My Day](#) by Jamie Lee Curtis. Published by HarperCollins Juvenile Books, 1998. ISBN: 0060245603, \$13.95.

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.childsworld.com. 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.

What's the Big Secret: Talking About Sex with Girls and Boys by Marc Brown and Laurie Krasny Brown, Ed.D. Published by Little Brown and Company, 2000. ISBN: 0316101834, \$5.95.

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*.

The Care and Keeping of You: A Body Book for Girls by Valorie Lee Schaefer. Published by American Girl. ISBN: 1562476661, \$9.95. www.americangirlstore.com.

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.

The Period Book: Everything You Don't Want to Ask but Need to Know by Karen & Jennifer Gravelle. Published by Walker and Company, 1996. ISBN: 0802774784, \$8.95. www.newmooncatalog.com.

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.

What's Happening to Me?: An Illustrated Guide to Puberty by Peter Mayle. Published by Lyle Stuart, 1981. ISBN: 081803128, \$9.95.

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

It's Perfectly Normal: Changing Bodies, Growing Up, Sex, and Sexual Health by Robbie Harris. Published by Candlewick Press, 1996. ISBN: 1564021599, \$10.99.

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

What's Happening to My Body: A Book For Boys by Lynda and Area Madaras. Published by Newmarket Press, 2000. ISBN: 1557044430, \$12.95.

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.

What's Happening to My Body: A Book For Girls by Lynda and Area Madaras. Published by Newmarket Press, 2000. ISBN: 1557044449, \$12.95.

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*.

resources resources

Sexuality: Your Sons and Daughters with Intellectual Disabilities by Karin Melberg Schwier and Dave Hingsburger. Published by Brookes Publishing Company, 2000. ISBN: 1557664285, \$24.95.

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.

Shared Feelings: A Parent's Guide To Sexuality Education for Children, Adolescents, and Adults Who Have a Mental Handicap by Diane Maksym. Published by Roher Institute Kinsman, Inc., 1996. ISBN: 092012918, \$14.00.

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 Roher Institute at www.indie.ca/roher/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, 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. 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.

Life Horizons I & II by Winifred Kempton. Published by James Stanfield Company. www.stanfield.com. 800-330-5851. Approximately \$700.00 for a set.

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

Just Say Know!: Understanding and Reducing the Risk of Sexual Victimization of People With Developmental Disabilities by David Hingsburger. Published by Diverse City Press, 1995. ISBN: 1896230008, \$15.00. www.diverse-city.com.

A wonderful resource for parents or professionals, this book provides straight forward 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.

Protecting the Gift: Keeping Children and Teenagers Safe (and Parents Sane) by Gavin De Becker. Published by Dell Books, 2000. ISBN: 0440509009, \$11.95.

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.

No-Go-Tell! Published by James Stanfield Company. www.stanfield.com. 800-330-5851. Approximately \$399.00 for a set.

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

Hand Made Love: A Guide for Teaching About Male Masturbation by David Hingsburger. Published by Diverse City Press. www.diverse-city.com. \$45.00.

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

Before She Gets Her Period: Talking with Your Daughter About Menstruation by Jessica B. Gillooly. Published by Perspective Publishing. ISBN: 0962203696, \$13.95. www.family-help.com.

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.

Beginnings : A Parent/Child Sexuality Program For Families With Children Who Have Developmental Disabilities by Terri Couwenhoven. Published by Wisconsin Council on Developmental Disabilities, 1991. www.wcdd.org \$3.00.

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

Changes in You by Peggy Siegel. Published by James Stanfield Company. www.stanfield.com. Approximately \$299.00.

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.

Janet's Got Her Period. Published by James Stanfield Company. www.stanfield.com. Approximately \$399.00.

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

Circles by Leslie Walker-Hirsch. Published by James Stanfield Company. www.stanfield.com. Approximately \$599.00.

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). 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

Stacking The Deck: A Social Skills Game For Adults with Developmental Disabilities by Richard M. Foxx and Martin J. McMorow. www.researchpress.com. \$19.95.

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.

Mind Your Manners. Published by James Stanfield Company. www.stanfield.com. \$399.00.

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.

Delicate Threads by Debbie Staub. Published by Woodbine House Publishing, 1998. ISBN: 0933149905, \$16.95.

By comparing observations to current theories of childhood friendship, 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.

How to Use the Volume 4 Index

This issue of *Disability Solutions* marks the end of our fourth publishing year. This supplement contains an index of the articles, reviews, and resources included in the last 6 issues of *Disability Solutions* (including this one) to help you find articles at a later date. It is our hope that *Disability Solutions* will continue to be helpful to you, or someone you know, long after the month it is published. You may want to remove this section (three pages) to use as a separate guide.

In this index supplement we have listed articles by their subject (some have more than one) and their title. Resources and books that have been reviewed are listed by the publication title. After each subject or title, you will find the volume number (they are all volume 4), issue number, and page number where it was published. For example, “How Was your Day?’ Designing Home-to-School Communication for Your Child, 4:2, 9-15” means that the article, “How Was Your Day?’ Designing Home-to-School Communication for Your Child” can be found in volume 4: issue 2, pages 9 through 15.

If you see an article or information in the index from an issue that you do not have, you can either download it from our web page (www.disabilitysolutions.org) or send a request for a printed copy for \$2.50 per issue. We have a limited supply of printed back issues and may not be able to meet everyone’s needs, but we will try our best.

We hope that *Disability Solutions* has been, and will continue to be, a valuable resource for you. If you have comments or suggestions, we welcome your input.

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What’s Happening to Me? An Illustrated Guide to Puberty,

The San Francisco Foundation
Community Initiative Funds
Creating Solutions
14535 Westlake Drive
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Disability Solutions

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