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Becoming a Woman: Teaching Healthy Sexuality to My Daughter

by Terri Couwenhoven

I think one of the most important things related to helping my daughter grow into a sexually healthy adult has been figuring out how to *help her feel good about who she is as a human being*. This sounds easy, but really is and was quite challenging for us. Let's face it, for the most part our society values intelligence, outer beauty, speed, and efficiency. Just count how many times in a day other people talk and brag about how intelligent, brilliant, "advanced" or "high functioning" their babies, kids, teens or other adults are – it will amaze you. As much progress as we've made integrating people with intellectual disabilities into the world, we have a long way to go. We must not forget that the experiences our sons and daughters have living life with a disability are not the same as ours. They are stared at, talked to differently, treated younger than their same-aged peers, and often discretely ridiculed when we're not around. This influences and shapes self-esteem in such a dramatic way that we can't just pretend our sons and daughters are "just like everyone else." Anna figured this out way faster than I did and her experiences manifested in her not wanting to have Down syndrome at one point in time. She told me she preferred being a "regular kid" (her words not mine). This was difficult, really difficult. I wanted her to grow up proud of who she was, including feeling okay about having a disability. Besides, isn't loving yourself the foundation for healthy sexuality in adulthood?

The work and support required to help her feel good about herself began in pre-adolescence and required many discussions about her disability, helping her understand Down syndrome and how her disability affected her uniquely, and offering strategies that would help her in life. My work (eventually her work) involved identifying gaps in knowledge and skill levels that would help her become more socially appropriate so she was more accepted, as well as helping her figure out how to have an active social life. It became clearer to me in adolescence that her peer group would be other teens with disabilities. Exploring clubs, activities, and groups where she could belong and feel good became a part of the process. I began to realize that she needed to have meaningful connections with others and to feel like she belonged to something outside of the family. The older she became, the more she became my guide on what she needed to feel okay about herself and her disability. The road was bumpy, but in her adult life she is pretty proud of who she is and has become.

The other idea that's been important related to sexuality is *thinking of my daughter in her chronological age vs. developmental age*. I have noticed that regardless of her cognitive disability, Anna has been pretty much on track with most everything related to sexuality: physical development, experiencing sexual feelings and crushes, her desire to date and have a boyfriend, and current aspirations to have a serious, long-term relationship as an adult. She hasn't always understood how to manage these developmental benchmarks or acted appropriately as she moved through these stages, but my job as a parent has been to prepare, educate, facilitate, and identify her needs for support as she developed and matured in the same way her peers did. Thinking about her this way has helped greatly. I have noticed that when I think about her chronological age, treat her that age, and have expectations for that age, she has grown and matured in ways I never imagined. She surprises me often. Her developmental age helped me understand how to adapt and modify messages and teaching so it would be more useful and understandable, but otherwise it was irrelevant.

Teaching sessions about sexuality and relationships have evolved over the years in a variety of ways. The younger my daughter was, the briefer, simpler, and more concrete the rules. For example, rules about who she could talk to about her periods were very specific (her teacher and me). Or understanding the appropriate level of affection when greeting someone new (a handshake vs. a bear hug) required sharing a simple rule, some role modeling, then her practicing in a variety of social situations. Now, as an adult, the topics are more complex and the rules aren't always so simple. For example, understanding how to determine if a relationship is healthy or exploitative not only requires teaching, but also an ability to make decisions and problem solve.

The other change in teaching has been that the content has changed from what I think she should know to more self-directed topics. A short time ago Anna asked me, "Am I old enough to date?" (she was 20 at the time). I said, "Yeah, you're old enough to date." She stated she was glad and then named the person she wanted to start dating. She decided what she wanted to learn and figure out related to dating. It seems to have become more self-initiated, which indicates she is understanding her rights to information about sexuality.

In adolescence and into adulthood, I have found teaching/information provided by another adult can be helpful, powerful and impactful. Our kids are similar to other kids in that they tire of us being the teacher all the time. Having another skilled professional share information in understandable ways, especially in adolescence and adulthood, can be beneficial and refreshing. Repetitive messages from multiple sources is always a good thing.

As parents we have learned so many things raising Anna and my other daughter, but here are some of the lessons I keep coming back to:

- You don't have complete control over how and when your son or daughter learns about sexuality. I used to tell myself, "I really should set up my laptop and create a presentation on relationships and boundaries because she needs some help with that." And then naively think that Anna's needs would wait until I was ready to share the information. It became clear to me, however, that learning from peers, television and other sources was a daily event and incredibly influential. Watching her same-aged peers flirt and incessantly talk about boys, and her repeated exposure to the sexual innuendoes on television (yes, even on the Disney channel!!), were contributing models for social behavior whether appropriate or not. If your child is out in the world experiencing life (hopefully they are), they will begin to interpret their world in their own way and will likely need guidance understanding social rules and relationships on their own time schedule, not only when you're ready.
- One discussion or teaching session is never enough. Learning and understanding what it means to be a sexual human being is a complex, life-long process. One teaching session, experience, or "talk" is inadequate. Our sons and daughters need lots of opportunities to learn and practice skills, ask questions, make mistakes, and have people in their lives who are willing and open to address sexuality issues. Your ability to be "askable" and provide coaching throughout life is a gift we can give all of your sons and daughters.

For this article I asked Anna what's been most important to her as we've talked about sexuality over the years, her view of how those talks have changed as she's grown up, and important lessons she's learned along the way. I'll close with her responses:

- *What's been important?* "I've learned a lot growing up, but I think learning how to take care of my body by myself was important. I got to go to camp overnight and spend time with my friends when I could take a shower by myself."

- *How have our teaching talks changed?* “My mom was an excellent teacher and now she is my coach.”
- *What lessons have you learned?* “I have learned to do the right thing. I have made mistakes. Now I know how to behave myself, act appropriate so people aren’t embarrassed to be around me. If you need help or are not sure what the rules are, ask someone for help.”

Terri Couwenhoven is a certified sexuality educator for people with disabilities and the parents and professionals who support them, and is based in Port Washington, Wisconsin. She is author of the award-winning book, “Teaching Your Child with Down Syndrome About Their Bodies, Boundaries and Sexuality: A Guide for Parents and Professionals” published by Woodbine House. She may be reached at 262/284-5043 or tcouwen@execpc.com. Anna is a self-advocate with Down syndrome. She works in the community, enjoys participating in summer theatre, listening to music, dancing, writing, and hanging out with friends.

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Destination – Adulthood: Preparing Your Child for Puberty and Adolescence

by Sue Fager

"What's this about an eruption?" the shy but determined fourth grader asked his parents. When it comes to the changes of puberty and adolescence, misinformation and uncertainties abound whether one is a youth noticing changes to his or her body or a parent considering how to begin talking about it. Conversations about the physical, emotional, and social changes that accompany puberty and adolescence can be among the most difficult facing parents and youth. This journey to puberty, through adolescence, and into adulthood is one every child will make, including children living with a disability.

While the task of preparing a son or daughter for adolescence may seem overwhelming, thoughtful preparation and adapting information for the specific child can make the preparation easier. Parents and care providers may already be using tools and strategies that can assist with the process. They may also find reassurance in knowing that youth consistently say that they want to learn about adolescence from their parents and that their family's values and cultural beliefs are important to them.

Developing a Plan

A good first step in preparation is for parents, care providers, and those who may be supporting them to ask themselves the following questions:

- What do I know?
- What do I still need to know?
- Where can I find more information?
- Who else can help me?

Together, parents, care providers, and support teams should decide what information – including family beliefs, values and culture – will be shared at each developmental stage of the child's life and who will share it. Next, parents and care providers should consider these questions:

- What information does my child already have?

- What information does my child still need?
- How quickly is the information needed?

Children should learn about physical changes before they go through them, with plenty of time to prepare. Strategies should be matched with a child's preferred learning, information processing, and communication styles to ensure that the information presented is understandable. In the remainder of this article are some specific approaches that may be helpful in communicating the information identified in the plan.

Using Task Analysis and Story Boards for Personal Care

The arrival of puberty brings changes to personal care routines and the need for increased independence in either carrying them out or in directing the person who will be assisting with them. Personal care tasks may consist of many steps that need to be done in a particular order – mastering them may prove difficult without support. Task analysis and story boards are two tools that may be helpful. Task analysis examines a particular self-care task and breaks it down into manageable steps; story boards can be used to illustrate each step and then posted in a convenient place to act as a reminder. For example, for a girl who is learning about managing her period, task analysis can be used to break the task of changing a pad down into sequential steps, which can be illustrated with drawings, photographs or the symbols used in her communication device. The story board can be placed in the bathroom and she can carry a photocopy in her purse to remind her at school until she has mastered the task.

Reassuring and Rehearsing

Adolescence brings changes for boys, too, such as spontaneous erections. Sometimes boys with disabilities who don't yet know this is a natural part of growing up think that an erection is related to their disability, which can deepen their sense of being "different." One approach parents and care providers may find helpful for explaining these events and how to manage them is to reassure and rehearse. By explaining what spontaneous erections are, and communicating that they happen to boys as a natural part of growing up, adults can reassure a boy that this is an expected part of maturing. And through rehearsing they can talk together about possible specific situations that may occur and explore options for what he can do to manage them. One example of part of such a conversation is this:

Son, soon you will be a teenager! As you continue to grow, you will notice some changes to your body, including your penis. You've probably noticed that your penis can become hard sometimes. That's called an "erection." This is something that's a natural part of growing up for boys. Sometimes it can happen when you are in a public place such as at school. Because your penis is a private part of your body and we have rules for how we take care of it, let's talk about what you can do when it gets hard at school so that you can manage it without embarrassing

yourself or someone else.

If you are at school and you have an erection while you're sitting at your desk, one thing you could do is stay at your desk until it settles down. That way no one but you will know what is happening to this private part of your body. Can you think of some other times when it might happen at school? What else could you do to make sure you're the only one who knows it's happening at those times? If you want we can practice what you will do when you get an erection in a public place like school.

Illustrating Personal Boundaries with Circles Charts

Skills needed to successfully navigate social interactions change drastically as a child matures and can prove difficult to acquire. There are societal and cultural expectations of appropriate adult behavior that youth must master to prevent them from making social errors with potentially serious results. Understanding the abstract concepts of personal space and appropriate intimacy may be illustrated with a Circles Chart (a tool developed by Leslie Walker-Hirsch & M.P. Champagne, 1993). The chart is a series of concentric circles with a different category of relationship assigned to each circle. The center circle is the youth; the next, immediate family members and partners; then personal caregivers, friends, teachers and other professionals, acquaintances, and, lastly, strangers. As the people in a youth's life are assigned to different circles, appropriate touching and hugging rules for each circle can be reviewed and reinforced. Illustrations or photos of specific categories of people can be added to a large copy of a chart to further illustrate the concept.

Using Numbers to Explore Behavior

With adolescence comes expectation for understanding how one's actions impact others and the results of those actions – two very abstract concepts. Teachers Kari Dunn Buron and Mitzi Curtis have developed a series of 5-point scales to use in helping students understand their emotional responses to situations, create positive behaviors in response, and maintain appropriate social boundaries. In Kari's book, *A 5 is Against the Law* (2007), the scale is used to teach social behaviors and boundaries, and the concept that behaviors that may have been tolerated when they were younger can actually be against the law when they're an adult. In this model, a "1" is very informal social behavior, the ways most people first notice each other. A "2" is reasonable behavior, the way people act when they are enjoying each other's company. A "3" is odd behavior that can make people uncomfortable. A "4" is scary behavior, like swearing or staring that could get a person expelled from school or fired from a job. A "5" is physically hurtful or threatening behavior that may result in going to jail. Using this scale, youth, with the assistance of their parents and support team, can examine and rate their behavior to understand social boundaries and the unintended consequences of communication and other interactions.

Practicing Askable Parenting and Teachable Moments

Not every strategy just presented is appropriate for every child. However, two that are helpful for every parent and care provider include being an "askable parent" and using "teachable moments."

Being an askable parent means that your child considers you to be approachable and open to questions – even the difficult and uncomfortable ones. Parents and care providers can take the initiative by asking open-ended questions, truly listening to their child's response, not judging, and engaging in two-way communication that supports a child's learning. Maintaining a calm demeanor is imperative – children learn just as much from how an adult responds and what they don't say. If a parent or care provider cannot answer a youth's question, they and the youth can search together for an answer. Depending upon the question, parents and care providers may need to consult professionals or representatives from disability-specific organizations that support adults living with disabilities. Finally, being askable means understanding the information youth need at a particular stage in their development, and providing it in the way that best suits their learning and processing preferences, and reflects their developmental age.

Starting conversations about puberty and adolescence can feel awkward. Everyday occurrences, or "teachable moments," can be used to expand opportunities for discussions and skill development. Underwear ads in magazines can provide an opportunity to reinforce public and private concepts by discussing the private parts of the body that are covered by underwear and where it is acceptable to wear only underwear. Watching TV and movies together provides great opportunities for parents and youth to explore the social situations depicted and discuss how a youth might react if faced with a similar situation.

Preparing Now

One of the greatest gifts we can offer our children is permission and support to grow up. The parents and care providers of youth living with disabilities may find it difficult to think ahead to their child's adulthood, yet doing so is important. Preparing for this journey can help parents and care providers feel more comfortable and confident. Helping youth prepare for and understand their own journey into puberty and adolescence will help them become fully accepted, fully participating adults in their community.

Note: Much of the information in this article came from the PACER Center's Family Advocacy and Support Training project, funded by the Administration on Developmental Disabilities at the U.S. Department of Health and Human Services.

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Sexuality Meets Intellectual Disability: What Every Parent Should Know

by Leslie Walker-Hirsch

The word "sexuality" is an emotionally-loaded one! The word "disability" is also. What happens when they are combined?

Many people want to equate sexuality education with permission to be sexually active. This is *not* so!! Sexuality education is the opportunity to learn, understand, and practice what it means to be either a man or woman in the culture and time in which we are living. And it's an opportunity to receive instruction about how to live happily, safely, and responsibly as an adult.

In the bad old days, sexuality and disability were rarely paired together in polite discussion. The view was that it was not acceptable to discuss sexuality openly. And people with disabilities were frequently hidden away and not mentioned either. Since that time, we have learned much about the benefit of talking about sexuality, and much has changed about how people with a disability are perceived.

Parents no longer ask, "How can I stop sexuality from developing in my child with an intellectual disability?" Instead we are asking, "How can I help my child with an intellectual disability express sexuality in a way that is consistent with his or her ability and within the standards of the community in which we live?" A much better question!!

Social/Sexual Development

Sexuality is an inherent and important aspect of everyone's personality and is not tied to IQ. However, there are both similarities and differences between how typical children's sexuality develops and how sexuality develops among children with intellectual disabilities.

Physical development of children both with and without an intellectual disability is quite similar, with puberty likely to occur earlier than in past generations for both groups. Although the biological maturity of young people with an intellectual disability is likely to keep pace with that of typical children, the social, emotional, intellectual and experiential maturity is most likely to lag behind that of typical children. The implication of this situation is that there is now a greater than ever disparity between biological age and social, emotional, intellectual and experiential age for children with intellectual disabilities. Children with intellectual disabilities are being asked at a younger age to respond socially and emotionally to a physical body that is likely to be much

more developed than the rest of their abilities. Additionally, these same young people are included with same chronological-aged children in schools and social activities. They are expected to cope and behave as appropriately as their same-age peers without disabilities. When that does *not* happen, schools and families get together to figure out what to do, but are often at a loss: Everyone wants to include the child with an intellectual disability, but also wants that child to be protected from making serious errors related to sexuality, and from being victimized by others who may try to take advantage of the child's sexual vulnerability.

Colleges and universities typically do not include sexuality education of children and teens with intellectual disabilities in the required preparation of special education teachers, or social workers and psychologists either for that matter. While special education teachers are well-versed in the aspects of addressing the unique learning styles of their students and the variety of teaching methods that have proven successful, they are not equipped, not comfortable, and often not permitted by their school boards to provide sexuality education to their students. Health education teachers are charged with providing sexuality education to their typical students and are well prepared to do that successfully, but they are not skilled at using the special education teaching strategies to teach students who learn differently. Consequently, there is a gap into which many students fall.

Sexuality education for school-aged children with intellectual disabilities is an important aspect of their social education that can get overlooked in lieu of academic skills. What would constitute a meaningful sexuality education for this group of children and teens? They need similar information to that of typically- developing peers, but the emphasis and teaching strategies need to be different. The "soft skills" and the development of social judgment ought to be a higher priority than reproductive system information. The opportunity for repetition of concepts and rehearsal of the associated behaviors needs to be built into a safe, judgment-free environment where they can effectively practice social, interactive and relationship skills.

Six Key Components of Meaningful Sexuality Education

Social and sexuality education must successfully address each of the following six key components, using teaching strategies that are age and ability appropriate. It must stress the learning strengths of the child and provide opportunity for repetition and practice of the social skills needed for success. The six components are as follows:

- *Adult Self-Care*: Grooming, toileting, dressing and accomplishing age-related hygiene and personal care.
- *Anatomy and Physiology*: Biological and physical aspects of sexual body functions and names, and distinguishing sexual anatomy from other body parts.
- *Empowerment*: The self-determination and self-valuing that the child is internalizing, and the influence that child can exercise in determining the extent to which he or she can be in charge of life choices.

- *Relationships*: Differentiating the social boundaries of the various relationships that a child is likely to have, and the requirement to adjust his or her behavior accordingly in the domains of touch, talk, trust and others.
- *Social Skills*: The ordinary skills of manners and politeness, as well as the skills of expressing affection to others and welcoming or rejecting affection expressed to them by others.
- *Social Opportunity*: The kinds of friendships, recreation and community participation that are available to each child. It must be matched to the social mastery of the child and his or her degree of independence. It must reflect the risk tolerance of the child and family as well as the benefit of that participation.

Parents' Roles

What can a parent do to assure that this kind of meaningful sexuality education is offered to their child? The following are some suggested actions:

- Be part of your child's team with teachers and/or professionals to develop a realistic plan for your child's social, educational, and recreational needs. Suggest a Social Development and Sexuality section in your child's IEP, IHP or other planning tool.
- Make sure your child knows that it is always safe to discuss any aspect of his or her life with you without fear that you will be punitive, judgmental or mocking.
- Support school-sponsored inclusive social events, as well as specialized social and recreational activities, by being an active volunteer.
- Be a role model to your child by demonstrating honesty, respect and appropriateness in your own relationships.
- Raise your child's awareness of appropriate social behaviors and boundaries by complimenting positive social interactions in which you see him or her engaged.
- Use the "teachable moment" as a learning opportunity about relationships and sexuality when watching TV or a movie, or spending informal time with your child.
- Participate in opportunities for parents to review sexuality education curricula that are being considered by your child's school district, and/or suggest curricula that are already available for learners with unique learning styles and special educational needs.
- If meaningful sexuality education is not offered at your school, help your child to access it in other locations in your area, such as the "Y", a family planning agency or an advocacy organization.

- Learn more about sexuality and intellectual disability by reading recommended works, and attending workshops by credible organizations such as Arc chapters, affiliates of the National Down Syndrome Society, Planned Parenthood, Parent Training and Information Centers, or your local college or university.
- Work one-to-one with your child to practice self-care related to sexual maturing, such as during menses, and prepare your child for the changes that will happen physically and emotionally as puberty advances. Be sure to emphasize the social skills associated with private self-care.
- Provide both medical and adult slang terminology related to sexual anatomy, and discuss when and with whom each kind of language is appropriate to use. Remind your child that sexual words must not be used to express anger or hurt another's feelings.
- Empower your child by providing opportunities for making decisions that grow with the maturing child, decisions such as what to have for lunch, what color sweater to wear, and who to invite to a movie.
- Know the signs of sexual abuse and know what to do if you suspect your child has been a victim (for more see *Impact: Feature Issue on Violence Against Women with Developmental Disabilities* at <http://ici.umn.edu/products/impact/133/default.html>, or go to <http://qualitymall.org> and search by "sexual abuse").
- If needed, do not hesitate to get professional help for your child in this aspect of development.
- And above all respect your child's sexuality as he or she moves toward maturity and into a safe, responsible, and satisfying adult life.

Conclusion

When sexuality education is provided to children and teens with intellectual disabilities in a way that they can understand and use, their teachers and families have reported improved social behavior and expect they will be safer from sexual ridicule and exploitation. When planning for a child's educational and social future, it is crucial to include meaningful sexuality education.

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Top 10 Reasons Why Age-Appropriate, Meaningful Sexuality Education is Important for Youth and Adults with Intellectual Disabilities

- 10 People with an intellectual disability need to have the same information that everyone else has.
- 9 People with an intellectual disability, but without sexuality education, are at a disadvantage in the workplace, in school and in their community.
- 8 People with an intellectual disability are safer from sexual abuse if they have training in recognizing and reporting sexual encroachment.
- 7 Even if a person is delayed intellectually, the person's body, emotions and spirit are probably NOT delayed.
- 6 Sexuality education overcomes fears by replacing frightening urban legends with accurate factual information.
- 5 Sexuality education adds to the quality of a person's life. It is the cornerstone for successful community employment, mutual relationships and independent community living.
- 4 EVERYONE grows older, but it is more important to GROW UP!! And isn't that what we really want young people to do?
- 3 Sexuality education should not only come from Ms. Lola on the XXX site on the Internet or from Hustler magazine.
- 2 We live in a sexualized world, whether it is TV, movies, advertisements, the mall, the supermarket... and even Disney!!! Yet parents are the first and most important influence upon their child's social and sexual development.
- 1 And the #1 most important reason why people with an intellectual disability need sexuality education is because: **SEXUALITY IS A NORMAL, EXPECTED AND JOYFUL PART OF OUR CULTURE AND OUR HUMANITY AND OUR LIVES.**

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Parents' Roles

What can a parent do to assure that this kind of meaningful sexuality education is offered to their child? The following are some suggested actions:

- Be part of your child's team with teachers and/or professionals to develop a realistic plan for your child's social, educational, and recreational needs. Suggest a Social Development and Sexuality section in your child's IEP, IHP or other planning tool.
- Make sure your child knows that it is always safe to discuss any aspect of his or her life with you without fear that you will be punitive, judgmental or mocking.
- Support school-sponsored inclusive social events, as well as specialized social and recreational activities, by being an active volunteer.
- Be a role model to your child by demonstrating honesty, respect and appropriateness in your own relationships.
- Raise your child's awareness of appropriate social behaviors and boundaries by complimenting positive social interactions in which you see him or her engaged.
- Use the "teachable moment" as a learning opportunity about relationships and sexuality when watching TV or a movie, or spending informal time with your child.
- Participate in opportunities for parents to review sexuality education curricula that are being considered by your child's school district, and/or suggest curricula that are already available for learners with unique learning styles and special educational needs.
- If meaningful sexuality education is not offered at your school, help your child to access it in other locations in your area, such as the "Y", a family planning agency or an advocacy organization.

Top 10 Reasons Why Age-Appropriate, Meaningful Sexuality Education is Important for Youth and Adults with Intellectual Disabilities

- 10 People with an intellectual disability need to have the same information that everyone else has.
- 9 People with an intellectual disability, but without sexuality education, are at a disadvantage in the workplace, in school and in their community.
- 8 People with an intellectual disability are safer from sexual abuse if they have training in recognizing and reporting sexual encroachment.
- 7 Even if a person is delayed intellectually, the person's body, emotions and spirit are probably NOT delayed.
- 6 Sexuality education overcomes fears by replacing frightening urban legends with accurate factual information.
- 5 Sexuality education adds to the quality of a person's life. It is the cornerstone for successful community employment, mutual relationships and independent community living.
- 4 EVERYONE grows older, but it is more important to GROW UP!! And isn't that what we really want young people to do?
- 3 Sexuality education should not only come from Ms. Lola on the XXX site on the Internet or from Hustler magazine.
- 2 We live in a sexualized world, whether it is TV, movies, advertisements, the mall, the supermarket... and even Disney!!! Yet parents are the first and most important influence upon their child's social and sexual development.
- 1 And the #1 most important reason why people with an intellectual disability need sexuality education is because: **SEXUALITY IS A NORMAL, EXPECTED AND JOYFUL PART OF OUR CULTURE AND OUR HUMANITY AND OUR LIVES.**

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