As this Impact issue is about to be published, one of the pioneers in sexuality education for persons with disabilities has just passed away. Her name is Winifred Kempton and one of the reasons this Impact issue is able to provide the depth and breadth of information it does is that she was among those who, over 40 years ago, publicly acted on her conviction that individuals with intellectual, developmental and other disabilities have the right and need to receive information about sexuality. The tools she created for sexuality education (including a dozen books as well as sexuality education programs she authored or co-authored) approached individuals with disabilities as fully-formed people with an intrinsic right to know about and participate in this part of the human experience. She was a genuine advocate in the truest sense, and will be missed.

Today, other pioneering voices are carrying on that advocacy and education work, and in this issue of Impact readers will have the opportunity to hear from some of them as they talk about the range of issues that are part of sexuality in its fullness. It’s our hope that the articles gathered here will provide information and inspiration that further support the right and opportunity for people with intellectual, developmental, and other disabilities to understand and express this essential dimension of human life.

Identity, Disability, and Sexuality: Reflections From a Son and His Father

by Nick and David Wilkie

We – Nick and David – are a colorful son and father duo who reside in the Twin Cities. We both work in the human services field. David (dad) works in health care and Nick works for the Metropolitan Center for Independent Living. For this article we were asked to reflect on the father and son conversations about sexuality we’ve had over the years. In order to write it we really needed to do some thinking about who we are, and the philosophical approach we have taken toward the topic and our lives. These are our reflections. We hope you enjoy them.

Nick’s Perspective

I feel very fortunate to have grown up in a household where my differences and challenges were not the first thing everyone talked about. This was a key part of the philosophy that my dad took on in raising me. When my dad would introduce me to people he would say, “I would like you to meet my son Nick,” and not, “I would like you to meet my son with a disability.” This was crucial in my identity development. To have that separation between me and my disability made all the difference in the world. Carrying that separation throughout the rest of my family and friends was challenging at times, but overall it proved to be very successful. Once family and friends saw that my disability did not change the way my dad saw me, or the way that he treated
Self-Advocates Speak Up About Sex

compiled by Karen Topper and Katherine McLaughlin

Members of the Green Mountain Self-Advocates in Vermont recently held a discussion group about sexuality for the purpose of sharing their thoughts and experiences in this article. Below are their responses to a number of questions about the messages they received about sexuality over the years, and why they think sexuality education is important. This is a record of the conversation as it occurred, and in some places they respond to one another, as well as to the questions. Their real names have not been used at their request.

Who first explained sex to you?

• Roy: My parents, then my friends in much, much more detailed discussion.
• Amber: I learned about sex in a sex education class by watching a movie in school, in 4th or 5th grade actually. I was mainstreamed.
• Rebecca: I have no idea. In school, it was like child development class or I want to say maybe in 6th grade.
• Justin: I got the talk from my cousin. He said this is what it is, now go do it.
• Gabrielle: Seriously, I’ve never gotten the talk.
• Molly: I’ve seen having sex on TV.
• Justin: Go on the Internet and you can find it. You watch any channel on TV and you can see it. It is on soaps.

What were the messages you got about sex from adults when you were growing up?

• Jennifer: Don’t have sex. And I agree with them. Don’t have sex. You will get pregnant and die. My parents would say, “Ou, ou, gross, sex.”
• Andrew: You’re not ready to have sex.
• Gabrielle: Make sure you are protect-ed before having sex.
• Andrew: You can’t handle having sex.
• Molly: My favorite one is, don’t have sex until you get married.
• Justin: You are not financially stable.
• Clara: Like if a guy has a disease in his body, you have to be careful of that.
• Amber: From the sexuality class I took last year, I learned to come right out and say it – “get tested” – because you don’t know what is out there.
• Ida: You can get AIDS and HIV. When I was in 6th grade we did a unit on AIDS and HIV. The best way to avoid that is abstinence, not to have sexual intercourse. They did it on HIV and Ryan White and hemophilia.
• Rebecca: Actually I was told if I kissed somebody I would get pregnant.

I learned about sex in a sex education class by watching a movie in school, in 4th or 5th grade actually. I was mainstreamed.

we watched a movie. I don’t know if it was about sex, but I think it was about reproduction.
• Julie: My Mom did talk to me. It was hard for her. It was kind of awkward for me.
• Molly: My grandma talked to me about sex. I don’t know why. It was awkward though.
• Elizabeth: I got the talk from my brother. It was awkward, embarrassing, but it was helpful.

• Justin: I got the talk from my cousin. He said this is what it is, now go do it.

Did you get any positive messages?

• Roy: That is was okay and natural.
• Kevin: My parents were always telling me it is a great, great thing, but be careful with it.
• Andrew: That it is fun.

• Elizabeth: My aunt told me it was refreshing.
• Henry: If you have sex, do it behind closed doors. Make sure they lock and nobody can come in.
• Ida: Puberty is part of becoming an adult.
• Rebecca: Yes, no one explained puberty to me. I had to learn it by myself.

I got my information from a special ed class, but other kids were jealous of me because of the information I got. It was better than the regular classes, which were just about diseases, that’s it.

• Ida: Especially for some of us for whom it was a surprise and we got it early. My period came early and I said what is this crap?
• Rebecca: Mine happened in a movie theater. I went in the bathroom and I said what is this mess?
• Clara: When I was young I read this book about becoming a woman. It talked about your feelings and your body.
• Adam: Looking back on the messages I got... Wrap your dick.
• Jennifer: I don’t get it? [someone explained it meant putting a condom on your penis].
• Adam: One that I got that was really helpful was sex is more than just inter-course.
• Andrew: It is not all about sex.
Did you get any positive messages, like you look really attractive, hot, you're sexy?

• Adam: Not as much in high school.
• Henry: Not really.
• Molly: This guy tried to pick me up and said I was good looking. And I don’t think I am good looking.

How did you feel about the messages you got?

• Molly: It felt like I was kid. I am 23 years old and I can do whatever the hell I want.

Did you ever notice if the messages you got were different than the messages given to your sisters or brothers?

[A resounding yes! Even from people who had been quiet up until this time.]

• Justin: Just because I have a disability it doesn’t mean I can’t have a normal relationship.
• Molly: I know my sister and brother got the talk. They don’t treat me like a normal human being.
• Amber: That is because you have a disability and they think you are not.
• Elizabeth: I can tell you, nobody is normal in this world.
• Andrew: What is normal?
• Justin: It is a dial on your washing machine.
• Andrew: Normal is just being yourself.

When people talk to your brothers and sisters and not you, what message does that give?

• Gabrielle: They wanted me to learn it on my own.
• Ida: They want to shelter you, protect you.
• Jennifer: All they say is, “Ou, don’t do it.” Thanks for helping me.

What was the most important thing you learned about sex from adults when you were growing up?

• Elizabeth: Wait until you are married for the first time.
• Gabrielle: If you want it, use protection.
• Clara: Find a good guy. Choose the right one and don’t do it spur of the moment.
• Adam: Sex is more than intercourse.
• Andrew: Make sure you are ready for it, ready for the responsibility.

What do you wish adults would’ve told you but didn’t?

• Gabrielle: If I had known everything that I know now, I probably would have waited.
• Ida: I wish they had given me an introduction to puberty.
• Adam: The only thing I can think of that I would have wanted to learn at an earlier age is what a vasectomy is. I don’t have other regrets because people did talk to me about 90% of it. I got my information from a special ed class. But other kids were jealous of me because of the information I got. It was better than the regular classes which were just about diseases, that’s it.
• Roy: The opposite of what they told me. They told me “don’t do it,” “be careful,” and “keep it in your pants.” Instead of making it so vague with one phrase sentences, say “It is okay.” Kind of give more of an explanation.

Why do you think people with disabilities need sexuality education?

• Roy: To get resources/tools to make healthy sexual choices.
• Molly: So that people know their rights.
• Andrew: Because we all have desires/needs and that’s okay.
• Clara: To get correct information.

My parents were always telling me it is a great, great thing, but be careful with it.

• Kevin: To get resources/tools to make healthy sexual choices.
• Roy: So that people know their rights.
• Molly: So people with disabilities don’t put themselves in bad situations.
• Julie: So we will know how to protect ourselves.

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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 strategies 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.

[Walker-Hirsch, continued on page 35]

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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.
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 expectations 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.

References


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Parents Talk About Sexuality and Disability: Highlights of PACER Cross-Cultural Focus Groups

by Julie Holmquist

What are the concerns and information needs of parents of young people with disabilities when it comes to their child’s sexuality? In seeking answers to that question, PACER Center, a national parent center for families of children and youth with disabilities or special health needs, recently conducted cross-cultural focus groups with parents of youth with disabilities ages 12-22 to gather their views about sexuality and disability.

Through nine focus groups conducted in 2009, 55 parents of culturally diverse backgrounds were surveyed in New York at Sinergia, Inc./Metropolitan Parent Center, and in Minnesota at PACER Center, to gather information for a new curriculum addressing sexuality and disabilities titled, *The Journey to Adulthood: What Parents Need to Know.* Taking part in the focus groups were parents, staff facilitators, and group recorders representing Somali, Hmong, and African American cultures, as well as the cultures of the Dominican Republic, Honduras, Puerto Rico, Mexico, and Ecuador. Parents answered five questions related to the area of sexuality:

- Has your son or daughter ever been attracted to another person?
- Has your child ever been in a relationship?
- How do you view your son’s or daughter’s physical/sexual maturity?
- Have you seen or known of people with disabilities who are in relationships?
- What information would be helpful to you?

Their responses, which provide a glimpse into parent concerns and information needs, are presented in the remainder of this article in the form of facilitator summaries of group consensus, as well as specific representative quotes.

### Attraction to Another

When asked, “Has your son or daughter ever been attracted to another person?” many parents of older children acknowledged that their children do show interest in the opposite sex. Responses included:

- Of course, they just have a disability!
- My son has been attracted to girls and describes what he likes about them – their eyes, the way they treat him.
- My daughter has said she likes her friend and that he is her boyfriend.
- In school, it causes a great deal of problems.
- My son likes girls. He wants to touch them, which is dangerous.

### Physical/Sexual Maturity

When the question, “Has your child ever been in a relationship?” was posed, most of the parents said no. Some commented that relationships would be likely to cause more problems and expressed worry that their children would not be able to form relationships. Others asked that the term “in a relationship” be defined: One parent stated that “a relationship for my child means ‘going steady,’ talking on the phone, e-mailing, getting to know the other person, or maybe going on dates to the movies on a weekend afternoon.” Many parents said they are dealing with other issues and do not think about the relationship issue, while some parents had specific concerns about their child’s relationship with the opposite sex, such as how to help them develop appropriate boundaries. Other responses included:

- Yes, I have problems establishing boundaries.
- My son, who is 14, has started asking questions or mimicking other kids about sexuality and gender differences. I never thought I would be speaking to my kids about how to interact with the opposite gender.

### Relationship Experience

When asked, “Has your son or daughter ever been in a relationship?” was posed, most of the parents said no. Some commented that relationships would be likely to cause more problems and expressed worry that their children would not be able to form relationships. Others asked that the term “in a relationship” be defined: One parent stated that “a relationship for my child means ‘going steady,’ talking on the phone, e-mailing, getting to know the other person, or maybe going on dates to the movies on a weekend afternoon.” Many parents said they are dealing with other issues and do not think about the relationship issue, while some parents had specific concerns about their child’s relationship with the opposite sex, such as how to help them develop appropriate boundaries. Other responses included:

- All humans are sexual beings.
- My son worries about looking good and he knows what has been explained to him. He knows how women get pregnant.
- I’ve prepared my son on the use of a condom and appropriate sexual behavior.
- My son knows that self-touching is private. I think he has the emotional maturity to be in a relationship.
- In our culture, you don’t talk to your kids about having a relationship. You talk to them only about getting married and having a family. However, I came to realize that we are not raising our children in our home
country. Therefore I changed my way of thinking. I will talk to my kids about relationships and puberty when they are the right age.

**People with Disabilities in Relationships**

When asked, “Have you seen or do you know of people with disabilities who are in relationships?” many said yes while others responded “never.” Most parents in two of the focus groups said no. Some parents were afraid that a relationship was beyond their child’s ability and said that a relationship should not even begin. Responses included:

- Yes, walking down the street and at a camp my child attended.
- I know of a couple with a child.
- I know of a group home where there are two or three couples including one gay couple.
- The thought of my child being in a relationship concerns me because I don’t want him being taken advantage of.

**Information Needs**

In response to the question, “What information would be helpful to you?” most of the parents expressed interest in workshops on sexual education in general that would address topics such as how to communicate about it, how to deal with issues of sexual abuse, and other related issues. One group of parents said they receive enough information from physicians and their families and did not need any other information. Another group was not comfortable with the subject. The facilitator of that group stated: “Even though they were answering the questions, I could clearly see by their reaction that they did not believe their children had a good chance of having a normal life. Also, paying attention to a child’s personal growth is not part of the culture.” Other responses included:

- How not to have fear about talking about sex to my kids.
- How to talk to girls about their first menstruation.

- How disability affects a loving relationship.
- To learn more about those who are married and their lives.
- How to teach children about sexual predators.
- How to teach children to communicate with parents about sexuality issues.

**Conclusion**

These focus groups were formed specifically to inform PACER Center as it responded to a need expressed by parents and parent groups across the county for curricula on this topic. “Discussion of puberty and sexuality can be uncomfortable for most parents, but it can be particularly difficult for parents and care providers of youth with disabilities,” according to Shauna McDonald, PACER’s Director of Community Resource Development. “Parents want to prepare their children with disabilities for the changes of adolescence, but many are looking for ideas and strategies to help them do this. We want to provide resources so parents can more easily teach their children about their changing bodies and how to maintain personal safety.”

The curriculum, The Journey to Adulthood: What Parents Need to Know, developed based on these focus groups, is currently being used in training by the 104 Parent Training and Information Centers nationwide as they work with underserved and underrepresented parents in their communities. It will also be available online in September 2010 through PACER Center at http://www.pacer.org.

Note: The curriculum was developed by PACER as part of the National Family Advocacy and Support Training (FAST) Project in collaboration with other parent centers and the FAST Partnership Board. The FAST project, funded by the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, helps families of youth with developmental disabilities become aware of and advocate for family support services as well as influence systems change. Its primary emphasis is on reaching underserved families from all geographic regions in the U.S. and its territories through the network of 104 parent centers.

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**Sexuality and Youth with Disabilities: Resources**

- **Talking About Sex and Relationships:**
  - The Views of Young People with Learning Disabilities (http://www.leeds.ac.uk/disability-studies/archiveuk/change/ final%20report%20read%20copy.pdf). This 2009 report describes the findings and research of the Sex and Relationships project at CHANGE, a national organization in Britain led by people with disabilities. Done in partnership with the Centre for Disability Studies at the University of Leeds, this project inquired about the views and experiences of young people with intellectual disabilities (referred to as “learning disabilities”) in the area of sex and relationships using drama work, interviews, focus groups, a national survey, and review of education resources.
  - Doin’ It: Sex, Disability and Videotape. The Empowered Fe Fes, a peer group of young women aged 16-24 with different disabilities, produced this award-winning video investigating sex and disability. In it they think about the topic from many perspectives by talking with activists and scholars. The viewer tags along on a date between a woman with a disability and her able-bodied boyfriend as they explore issues in dating with a disability over a candle-lit dinner. Available from Beyondmedia Education in Chicago at http://beyondmedia.org or 773/857-7300.
  - The Rules of Sex: For Those Who Have Never Been Told. By N. Baladerian, PhD & J. Nunez. This book, available in print or as a PDF is written with and for individuals who have never had a concrete description of “the rules of sex,” and may get or may already have gotten in trouble just for lack of information. Written for young adults. Available in English and Spanish from the Disability, Abuse, and Personal Rights Project of Spectrum Institute at http://www.norabaladerian.com/books.htm.
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 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...
What’s been important?
The full report, published by the National Center for
What lessons have you learned? “
How have our teaching talks changed?
• The condom was reported as the most commonly
ter, but here are some of the lessons I

raising Anna and my other
multiple sources is always a good thing.
and refreshing. Repetitive messages from
understandable ways, especially in ado-
and have people in their lives who are
will give all of your sons

In adolescence and into adulthood, I
have found teaching/information provid-
ed by another adult can be helpful, pow-
erful 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 ado-
lescence 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 daugh-
ter, 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 in-
fluential. 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 ex-
periencing 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
ever enough. Learning and under-
standing what it means to be a sexual
human being is a complex, life-long
process. One teaching session, ex-
perience, 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 some-
one 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@excpc.com.
Anna is a self-advocate with Down syn-
drome. She works in the community, enjoys
participating in summer theatre, listening
to music, dancing, writing, and hanging out
with friends.

Teens and Sex Today
A June, 2010 report titled “Teenagers in the
United States: Sexual Activity, Contraceptive Use,
and Childbearing” provides a thought-provoking
snapshot of some of the sexual attitudes and
behaviors of teens. While the report, published
by the National Center for Health Statistics, does
not specifically discuss teens with disabilities, it
does describe part of the social context in which
all teens are growing up. Among the findings of
the research conducted in 2006-08 were:
• 42% of never-married females and 43% of
never-married males aged 15-19 had engaged
in sexual intercourse.
• The most common first sexual partners were
someone with whom they were “going steady.”
The second most common was someone they
just met; this was more common for males.
• The second most common contraceptives
were

used method of contraception among sexually
experienced teen females; the second most
common was withdrawal, and third was the pill.
• Among both female and male teens who had not
yet had sex, the most common reason for not yet
having done so was that it was “against religion
or morals.” The second and third most common
reasons were avoiding pregnancy (second for
females, third for males), and waiting for the right
person (second for males, third for females).
• 58% of never-married females and 47% of never-
married males reported they would be “very upset
if they got pregnant/got a partner pregnant,
while 14% of females and 18% of males would be
“a little pleased” or “very pleased” if they got (a
partner) pregnant.

The full report, published by the National Center for
Health Statistics, is available at http://www.cdc.gov/
Overview

Sexual Expression for Adults with Disabilities: The Role of Guardianship

by Robert D. Dinerstein

For adults with disabilities, as for other adults, the desire to enter into intimate personal relationships, including sexual relationships, is one of the most profoundly personal rights there is. As The Arc and the American Association on Intellectual and Developmental Disabilities state in their Position Statement on Sexuality, “People with intellectual and/or developmental disabilities, like all people, have inherent sexual rights. These rights must be affirmed, defended, and respected” (The Arc & AAIDD, 2008). That desire is no less important for the many adults with disabilities who are under some form of guardianship.

To what extent does or should having a guardian limit an adult’s ability to fashion intimate relationships of his or her choosing?

Guardianship is a form of legal relationship in which a court appoints an individual (called the guardian or conservator) to protect the person or property of an individual (called the ward or the allegedly incapacitated person). In the U.S., guardianship has always been a creature of state law; there is no one guardianship law nationwide (as there is in other countries), but rather 51 guardianship laws (the 50 states plus the District of Columbia) (Dinerstein, 2006). Nevertheless, there are certain national trends in guardianship law, aided by such influential resources as the Uniform Guardianship and Protective Proceedings Act of 1997, which many states have adopted in one form or another (National Conference of Commissioners on Uniform State Laws, 1997).

Traditionally, guardianship in the U.S. was an all-or-nothing affair within the realm it functioned; that is, a guardian of the person was a general or plenary surrogate decision-maker over almost all aspects of an individual’s life, including residential, medical and lifestyle domains, while a guardian of the property would be in control of all financial aspects of the life of the individual with disabilities. Capacity – more usually called competency – was also thought to be all or nothing; one either had legal capacity (or was competent) or one did not (or was not competent), and if one did not, he or she needed a guardian to substitute as a decision-maker. Such a legal regime, in theory, maximized protection of the allegedly incapacitated person but had the distinct disadvantage of undermining the autonomy of the individual. Plenary guardianship was a kind of “civil death” in which the individual lost all rights to make the kinds of decisions that adults typically make in our society. In practice, guardianship could be even worse, in that some guardians (especially for elderly individuals) either ignored their wards or took advantage of them financially or otherwise.

Sexual and intimate relationships were included within the kinds of relationships over which plenary guardians exercised control. Of course, for adults with disabilities in institutions, opportunities to have intimate relations, especially with adults of the opposite sex, historically were extremely limited. However, as more and more individuals have left institutions, or avoided them altogether, and as societal attitudes toward the importance of sexual expression for adults with disabilities have evolved, the balance between sexual expression and protection from abuse and coercion has become both more complicated and more salient.

Today, the landscape of guardianship has changed significantly as a result of exposés in the media, congressional investigations, and developments in the fields of law, developmental disabilities, mental health and gerontology. Many state statutes emphasize that guardianship should not be used unless it is the least restrictive means to protect the interests of the allegedly incapacitated person. Indeed, many policymakers and advocates increasingly argue, in the U.S. and abroad, for supported decision-making rather than the surrogate or substitute decision-making that characterizes guardianship (United Nations, 2006). We now understand capacity to be contextual (decision-dependent as well as individual-dependent) and potentially fluid; a person without capacity in one realm (e.g., health care decision-making) may well have capacity in another (e.g., decision-making about residence), and a person without capacity today can receive training and be exposed to experiences that will enable him or her to have capacity tomorrow (Dinerstein, Herr & O’Sullivan, 1999). Less formal alternatives to guardianship, such as durable powers of attorney and health care proxies, are preferred to guardianship and should be explored and appropriately rejected before turning to guardianship at all. Even if guardianship is appropriate, courts and parties are urged to examine whether alternatives to plenary or general guardianship – such as emergency, temporary or limited
guardianship – may provide sufficient protection for the interests of the allegedly incapacitated person while increasing the amount of autonomy and decision-making authority he or she retains. Limited guardianship, in particular, has much to recommend it, because under limited guardianship arrangements, the only decision-making rights that the person loses are those that a court explicitly identifies in the order appointing the limited guardian. Under a limited guardianship, the lawyer for the allegedly incapacitated person (the adult with a disability) can make sure that the individual retains the right to make decisions about sexual relationships, birth control, and other intimate matters. Even if the right is not explicitly retained for the individual, the lawyer for the individual can insist that the limited guardian not be given authority within this area; the absence of explicit authority for the guardian would mean the individual would be able to make decisions about intimate relationships. States such as California, New York, and Vermont, for example, go further and specifically recognize in their statutes or regulations that the incapacitated person retains decision-making rights regarding sexual and social relationships unless a court orders otherwise (and sometimes not even then).

What if the adult has a general or plenary guardian (because notwithstanding the preference for limited guardianships, many potential guardians still seek, and obtain, plenary guardianships) – is the adult unable to make decisions in the area of intimate relations? Even in this situation, the adult with a disability retains important rights. Because of the highly personal nature of the right of intimate association, many argue that the allegedly incapacitated person must retain the right to make decisions regarding, for example, whether to use birth control and what method (Field & Sanchez, 1999). The influential National Guardianship Association Standards of Practice (National Guardianship Association, 2007) provide, in Standard 10-II.A., Sexual Expression, that, “The guardian shall acknowledge the ward’s right to interpersonal relationships and sexual expression. The guardian must take steps to ensure that a ward’s sexual expression is consensual, that the ward is not victimized, and that an environment conducive to this expression in privacy is provided.” Standard 10-II.E. goes further in requiring that the guardian “shall protect the rights of the ward with regard to sexual expression.” Even in situations in which the guardian makes a specific decision about the allegedly incapacitated person’s sexual relationships, under general principles of guardianship law the guardian is supposed to use the standard of substitute judgment – that is, the guardian should make the decision that he or she believes the incapacitated person would make if he or she had the capacity to make it – rather than a best interests standard (what the guardian thinks is best for the incapacitated person) or a standard based on what the guardian would choose for him or herself. This guardianship best practice is especially important given the personal nature of the rights involved for the adult with a disability.

Listening to the incapacitated person is especially critical because even if a court determines that the adult with a disability does not have sufficient capacity on his or her own to make the decision involved, the individual will undoubtedly be able to have some opinion about the decision and process some of the relevant information. Even adults with disabilities who cannot communicate verbally can demonstrate through their nonverbal conduct that they want to have a close or even intimate relationship with another person, for example, by going into a bedroom together to seek privacy.

Ultimately, the key question is whether the adult with a disability can make an informed decision, or give informed consent, to the relationship or activity being contemplated. Informed consent requires capacity to make the decision; knowledge about the decision; and absence of coercion (or voluntariness) (Dinerstein, et al., 1999). For some kinds of romantic relationships, like a hand-holding relationship, the level of risk is so low that relatively little capacity or knowledge is needed, and a plenary or limited guardian should have no or at most a limited role in decision-making. For more involved relationships, such as one that includes sexual intercourse, concerns about capacity, knowledge, and absence of coercion become more critical (Stavis & Walker-Hirsch, 1999). But those concerns do not mean that it should be the guardian’s decision whether the allegedly incapacitated person should have a sexual relationship with another. Rather, whether the guardian is plenary or limited, the better approach is for the guardian and person to discuss such issues as the nature of the relationship, the pros and cons of entering into it, the person’s knowledge about the acts involved, the importance of protecting one’s bodily integrity and autonomy, and the ability to change one’s mind if circumstances change. Whether parent, friend, limited or plenary guardian, or provider of supported decision-making, the person without a disability can play a critical role in helping the adult with a disability to have meaningful relationships that promote happiness while avoiding untoward risk.

References


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From a religious perspective, it is always important to ask, “What does God want?” Not that we have the ability to answer without doubt, but as people of faith we can keep that in mind as a guiding principle for the decisions we make and the values we seek to live out.

As we wonder about the blessings of life, including companionship, sexuality, and lifelong commitment, we have to ask, “Are those blessings reserved only for a select group or are they universal goals and privileges to which all, to the extent of their abilities, are entitled?” I believe that we must look for ways to extend these opportunities to all of God’s creation to the extent that it is possible. That is where religious organizations and institutions can provide assistance and attitudinal influence not only to individuals with disabilities, but to those who live with them.

Nothing could match the excitement and enthusiasm he felt on the day he walked into Temple to tell me he had met someone very special.

The path of life presents all of us with opportunities to pause and take a photograph that enters our life album. These pictures are only moments but they can mean so much more when we see them as markers of our growth and transition, which is, bottom line, what life is. Judaism has long recognized that the ceremonies and rituals in which we engage are tremendously wise ways to help us pause and savor each of those moments. Indeed, they teach us that every moment in life has the potential to take account of life’s richness and our human ability to enhance those moments to their greatest potential. This is something that should have no asterisk for a person with a disability.

I have been privileged to serve a congregation for nearly three decades in which we have, in numerous ways, sought to live out a commitment to including children and adults with disabilities in all areas of congregational life. But it was not until seven years ago that I had the opportunity to be involved in a situation that has remained embedded in my mind and heart as one of the most significant personal interactions I have been blessed to have in my rabbinate.

Robert, a man in his 40’s who has developmental disabilities, had been part of our community for many years. His sister and brother-in-law belonged to our congregation and his parents, who live in another city far away, had made arrangements for him to be part of our community. He would come and visit me from time to time, attend services on occasion (much like most congregants!), and would make special visits to share significant moments in his life, such as when he got a job or won a medal in the Special Olympics. He was so proud of those medals and the sports in which he had engaged to win them. He was filled with enthusiasm every time he started a new job. His life was filled with blessings, in spite of the fact that he faced severe challenges every day. He definitely struggled, but he had a perseverance that enabled him never to give up and inspired others around him as well.

But nothing could match the excitement and enthusiasm he felt on the day he walked into Temple to tell me he had met someone very special. Her name was Julie. She worked at the same place as he did and they had taken a liking to each other. One thing led to the next and they were in love. When he brought her to the Temple to introduce her to everyone who was there, we were all moved by their affection and caring for each other. They held hands, and smiled constantly. She wanted to study about Judaism so that they could have even more in common. Most important to her was to have her own “Hebrew name,” her official connection.

They started coming to services and classes frequently, always sitting in the front row so that they could have a good view of things, and the rest of the congregation noticed them and reached out to them at our post-prayer gatherings of conversation and food (we are a Jewish community, after all!).

I will always remember the day they came to talk with me about getting married. I must admit that because of my own preconceived notions, prejudice, and ignorance I wondered whether this was possible. Should people in such situations get married? In truth, I must have thought: Is this too much for me to handle?

In spite of that, I proceeded. As I do with all couples, I invited them to meet with me privately in my study and we began a long discussion that led to interaction with their therapist, a wonderful,
Robert and Julie stood under the chuppah and celebrated with their family and friends. On Memorial Day 2004, at Bet Shalom Congregation, Minnetonka, Minnesota, Robert and Julie stood under the chuppah, the decorated canopy that symbolizes the Jewish home that a couple establishes on their wedding day, and celebrated with their family and friends, many of whom, because of their own disabilities, had never been invited to be a bridesmaid or groomsman before. Never have I witnessed such pure joy, love, and happiness.

They continued to come to services and always sat in the front, eager to come up to the pulpit afterward and talk with me, reminding me that this was the spot on which they stood when they married. We clergy often talk about the power of ceremony and ritual and how they can serve through recall as sustenance. This was the clearest example of that.

They loved going on car trips and traveled together, she reading the map and signs, he driving. Together they were a fabulous team. To celebrate their first anniversary, they had made arrangements to have a special anniversary dinner, go swimming, and spend the night at the hotel where they had their wedding party. Their bags were packed early in anticipation. In their excitement they decided to go out for ice cream early in the morning of their big day. Tragically, on that morning their bliss ended. It was not because of a failure in their ability to maintain their relationship and caring, but in a terrible car accident in which they were hit by a driver under the influence. Julie was killed. After only one year of marriage Robert lost his beloved. They had worked so hard to achieve their goals and had created what could only be called a marriage filled with blessing and joy. Their marriage was, in my opinion, exactly what God wants.

Today, I often think of Robert and Julie when I meet with any couple contemplating marriage. Sometimes I wish for every couple with whom I counsel the simplicity of the love and caring that this couple so innocently and lovingly bestowed upon each other. Most of all I think of what a difference a religious institution and its leaders, clergy and laypeople alike, can make in fostering attitudes and extending outreach and support to all of God’s creation, serving as God’s partners in extending God’s blessings of love and joy to anyone who has the ability to experience them.

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On Memorial Day 2004, at Bet Shalom Congregation, Robert and Julie stood under the chuppah and celebrated with their family and friends.

## Resources on Faith Communities and Individuals with Disabilities

- **Caring Relationships: Helping People with Mental Impairments Understand God’s Gift of Sexuality**. By R. C. Vredeveld. Written from a Christian perspective, this book includes chapters on sexuality in relation to the Bible, the dimensions of caring relationships, sexual abuse, marriage, and a model for support that faith communities can use with married couples who have cognitive disabilities. Published by CRC (Christian Reformed Church) Publications and distributed by Faith Alive Resources (http://www.faithaliveresources.org) and other booksellers.

- **Friendship Ministries** (http://www.friendship.org). This interdenominational ministry helps equip churches to include people with intellectual disabilities. One model it offers is the Friendship program, a ministry with people who have intellectual disabilities that congregations can implement. Friendship Ministries provides the help needed to start local Friendship groups and materials to use in the weekly gatherings that bring people with intellectual disabilities and mentors together for social and spiritual nourishment.

- **The Jewish Community Guide to Inclusion of People with Disabilities**. By S. Christensen. This book provides a framework and strategies for use by any Jewish organization seeking to include individuals with disabilities in all aspects of congregational and organizational life. It’s published by the Minneapolis Jewish Inclusion Program for People with Disabilities, a program of Jewish Family and Children’s Service of Minneapolis, and available at http://www.jfcsmpls.org/pdf/inclusionordernew.pdf or 952/542-4838.

- **Religion and Spirituality Division of the American Association on Intellectual and Developmental Disabilities** (http://www.aaddreligion.org). On the division’s Web site are extensive resources from around the country related to spirituality and inclusion in faith communities for people with disabilities.
Finally, Acceptance

by Carol Ely

I must have been about 13 years old when I first started wondering if anyone would ever find me attractive enough to want to see me in a romantic sense... hearts, flowers, etc. I found out what everyone does: some yes, some no.

I certainly didn’t plan it one way or another, but with the exception of one person (my first love who had multiple sclerosis) the “romance” in my life has come from men who don’t have a disability. I’d heard the question of “disability or no disability” go both ways. Some people in my life felt that I should only date men who had one, thus eliminating the need to explain mine. Other friends thought it better to date someone who didn’t have one, so that I could be with someone who drives, or not have the hassle of dealing with two pieces of mobility equipment. There is no doubt that the argument can go both ways.

In my 20s and 30s I had a couple of female friends without disabilities who would call and offer to pick me up so that we could go out for drinks, a movie or wherever the night took us. At that point in life I did want to date a man without a disability; I thought it would be easier logistically. Unfortunately, as a young adult, the couple of times that I cared for someone enough to think about taking the steps to marriage, I learned that when it came down to the question of whether or not he could deal with my disability for the long haul, the answer was NO. Of course that hurt a lot, so I made the decision not to have another romantic relationship at all. It turned out that resolve lasted quite awhile – for nine years. After awhile I no longer thought about it one way or another, it just was. The women in my family who were closest to me believed that if you look for something you’ll never find it, including a man. So I subscribed to that theory too, although I also felt that looking would be pointless and the result the same as before.

One day I met David, a man without a disability, who started talking to me when I was finally comfortable enough to let someone get past, “Hello, how are you?” I had also ventured into unknown territory for me; we are from different ethnic groups. We had general conversations over a period of about three months, with me looking forward to them a little bit more each time. I began to wonder if he was ever going to ask me out or not. (I thought he was taking an incredibly long time to say something!) Finally, the day came and I did a little wheelchair happy dance in the privacy of my apartment.

At this point it’s important to me to mention that when we met about 10 years ago my disability posed few challenges in terms of being able to do most of my personal cares independently, though I did have a home health aide who came in to clean my apartment, do my grocery shopping, and help with a few daily living activities. So, I had quite a lot of time when I was available to see him at home without having to be concerned about anyone else being around. Of course it never occurred to me that my needs would change as I aged. Or that those changes would mean that I would need personal care assistance. However, because of past experience, I still thought he’d only be around for a month or two and then disappear because of my disability. Consequently, I didn’t think about a long-term relationship colliding with something I’m now very familiar with: aging and disability.

We were about four years into our relationship when I began to notice that it was taking me longer to do things that didn’t used to take much time. I used to be able to get in and out of bed and into my chair smoothly and efficiently.

However, after another year or so it took 30 to 35 minutes on some days. During the easier years, I used to be able to go from being showered to dressed in about the same amount of time; eventually I had to start getting up between 5:00 and 5:30 in order to be ready to leave for work by 8:00 in the morning. However, even that didn’t work after awhile and more often than not I wasn’t ready to go when my ride came to pick me up in the morning. Now, the home health aide who for a number of years had to help me with only a few personal cares was needed to get me in and out of bed and dressed in the morning. That was a big step down in the way I felt about myself. I was used to feeling strong and independent.

Since I’m older than he is I wondered if I was going downhill so fast that he wouldn’t stick around. He always came back with some version of, “I’m still here, aren’t I?”
There was no denying that my physical capabilities were undergoing a drastic change. But one thing in my life remained consistent: David. When I talked about the things I couldn’t do anymore he reminded me that there were aches and pains that he had now that he didn’t have when we met either. Since I’m older than he is, I wondered if I was going downhill so fast that he wouldn’t stick around. He always came back with some version of, “I’m still here, aren’t I?”

Then came the “big test,” at least as far as I was concerned: I had to have major surgery. Thankfully, I didn’t realize how much postoperative pain there would be beforehand or I would have been terrified. What followed was weeks of recuperation and selected visitors, though he wasn’t one of them because I felt and looked like I’d been in a train wreck and I didn’t feel like I wanted to see him. Of course this meant no intimacy either, which has always been high on the list for both of us. We talked a lot on the phone though, and I waited for the “this isn’t working for me anymore” conversation...but it never came. As I regained my strength after surgery, it was clear that we were both waiting for the day when closeness was on again.

So, where are we now? In a place where we both realize (especially me) that aging is inevitable and that doing it with a disability brings even more challenges. However, along the way I’ve also learned to speak up about the kind of support that I need from him and how to ask for it in a way that respects that even if he’s not overtly romantic, he understands that sometimes hearing something like, “For any man that hasn’t known you it’s his loss” goes a long way with me.

I didn’t think this would end up being a long-standing relationship, but since it is, I’ve learned a few things along the way:

- Long-term relationships of any kind mean that you should think before you speak.
- Not everyone says “I love you” in words all the time.
- For some people looks and the changes that come with aging really are a superficial thing.
- When environmental, physical and physiological things change and you still love, respect and want to be together (most of the time, anyway) that’s success.

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Sexuality and Adults with Disabilities: Resources Supporting Dating, Marriage, and Parenting

- The Riot! Healthy Relationships Issue (http://www2.hsri.org/docs/Riot_Issue_23.PDF). The January 2010 issue of this national e-newsletter by and for self-advocates focuses on intimate relationships. It is published by the Self-Advocate Leadership Network at the Human Services Research Institute, Portland, Oregon.

- Love Rolls On (http://www.loverollson.com). Loves Rolls on is a Web site created to inspire, educate and provide an insight into inter-ability relationships where one partner has a disability. It is operated by husband and wife Barton and Megan Catter, and includes a blog, articles, resources, and events.

- Quality Mall (http://www.qualitymall.org). Through a keyword search on this Web site over 150 resources on dating, sexuality, and marriage in relation to people with disabilities can be found. This national clearinghouse is operated by the Research and Training Center on Community Living, University of Minnesota.

- Parents with Disabilities Online (http://www.disabledparents.net). Created by Trish Day, a mom with a disability, this Web site includes extensive resources for parents with disabilities, people with disabilities who are planning to become parents, and nondisabled partners of parents with disabilities. It includes information on pregnancy and reproductive health, adaptive/adaptive parenting products, organizations, and toys, as well as stories by and an e-mail community for parents with disabilities.


- Disaboom (www.disaboom.com). This Web site for people with disabilities includes a number of articles by individuals with disabilities about their experience planning a wedding when the bride/groom uses a wheelchair (among them are “Do-It-Yourself Wedding Planning for the Bride or Groom in a Wheelchair” and “Wedding Planning Tips for Wheelchair Users”).

- Parenting with a Disability Network (http://www.cilt.ca/parenting.aspx). The network, based at the Centre for Independent Living in Toronto, is a peer support and information-sharing network for parents and prospective parents with a disability. On its Web site are numerous resources ranging from parenting publications on different life stages of children, to information on adaptive baby care equipment, to guidance for service providers in offering nurturing assistance for parents with disabilities.
A Sexuality Policy That Truly Supports People with Disabilities

by Perry Samowitz

It is now over a decade since Professor T. Robert Ames (deceased) and I wrote a scathing editorial in the AAIDD newsletter blasting the field for not effectively dealing with the sexual needs of people with intellectual and developmental disabilities (ID/DD). We wrote:

...there remains, for the vast majority of people with ID/DD, a major area of deprivation and inequality, a lack of opportunity, choice, and the inherent right to develop and participate in social relationships which may involve sexual expression. The barrier lies not in the inability to develop responsible social and sexual behaviors, but in the misapprehensions and collective negative attitudes of some administrators, professionals, family members and the uninformed general public.

They continue to support outdated laws and public and agency policies which deny people with ID/DD the opportunity to develop the requisite responsible social and sexual skills and behavior, to exercise choice, and to have the opportunity for meeting and relating. The issue is over-control and a denial of basic human rights. It is fundamentally abusive in its effect. The cumulative result of such repressive and arbitrary attitudes and policies is human suffering and degeneration. Most people with ID/DD have either had to give up

any hope of social/sexual fulfillment or, when possible, to surreptitiously seek partners and moments of gratification in dangerous, unlawful and degrading situations. (Ames & Samowitz, 1999)

What has changed in the decade since we wrote that article? Recently I was at a meeting with a number of psychologists and other staff members from a state system who said that they did not want the mentioning of sexual issues in a curriculum that will support people with ID/DD. They didn’t want “to open that can of worms.” When I asked why, they just laughed and said it was better not to go in that direction. Yet people with ID/DD have sexual needs that if not fulfilled have resulted in unhappiness and sometimes aberrant behaviors.

At YAI/National Institute for People with Disabilities we have always believed that sexuality is a normal part of a person’s personality, and that people with ID/DD have the same needs that all people have. There is an important concern about their ability to be able to provide informed consent when being involved in a sexual relationship, and that issue needs to be addressed in a professional, respectful manner. As Professor Ames and myself also wrote:

We all acknowledge that people with ID/DD, for the most part, require varying degrees of supports in many aspects of their lives, including some degree of protection from harm, abuse, and exploitation. They are certainly often in need of these supports and protection in social/sexual relationships and situations. This does not mean that they cannot make reasonable choices from an array of viable options, give consent to participate in responsible social/sexual behaviors with another consenting person and form fulfilling relationships.

Agencies need a social/sexual policy

In order for an agency that serves people with ID/DD to provide the necessary supports for the social and sexual dimensions of life, there needs to be a written social/sexual policy that clearly states the agency’s philosophy and how it is specifically going to be implemented by staff. Without a written policy, each staff member could theoretically impose his or her values on people with ID/DD. Imagine the confusion for a person with ID/DD if confronted with numerous opposing views from staff. We would never tolerate this if the issue was a behavioral intervention. Careful plans are written so there is consistent treatment. Yet the issue of sexuality is often avoided, which allows staff to fill the vacuum with their own values and prejudices.

A sexuality policy needs to start with a philosophy. Our stated philosophy at YAI is the following (YAI, 2004):

Sexuality is a basic biogenic need and integral to the total way in which an individual relates to his or her world as a male or female. It includes not just sexual activity, but also the acknowledgement of feelings, ways of relating to self and others, self-esteem, gender identification, and sexual orientation. Individuals with ID/DD share the need to love and be loved, and as consenting adults to establish relationships with person of their choice and to express their sexuality so long as they are not injuring themselves or others. Staff needs to be trained to help consumers develop healthy and functional expressions of their sexuality.

We also add, “To ensure that this happens, the agency will value the voice, and advocate for the rights, of people with ID/DD.” We always respect individuality, which includes culture, spirituality, gender/gender identity, and sexuality
(self-image, self-esteem, relationships, choice-making, sexual orientation), and we affirm that “Every individual has the right to be supported to develop loving and safe friendships and relationships.”

Beyond our philosophy, in our policy there are 11 specific social/sexual areas that are addressed. In the remainder of this article six of them will be discussed briefly: choices and consent, friendships and relationships, education and information, sexual expression, reproduction and contraception, and sexual behaviors (YAI, 2004). (Additional detail on these areas and others in our policy is available by contacting us at www.yai.org/resources or calling 212/273-6100).

**Choices and Consent**

It is written in the YAI policy that:

Adults with developmental disabilities have the right to make their own decisions about relationships. A person with a developmental disability has the right to engage in sexual activity with another person providing he/she is capable of providing informed sexual consent.

The issue of consent is very important. Without the ability to consent, even if a person is a willing partner, sexual activity is illegal. For the vast majority of typically-developing people, consent becomes automatic at an age specified by the state in which they reside or where they are having sexual contact unless they are in a comatose or other mind-altering state. For people who have ID/DD, there is no clear demarcation in determining their ability to consent. It is based on their individual capacity to understand the ramifications of their actions. At YAI, we have created tools to determine consent for people who reside in our residential programs and show an interest in being sexually active. Also, in our health clinics we provide consent determinations to people with ID/DD who live in residences from other agencies, live independently or live with their families. (It is very important to mention that we are located in New York state and according to our legal consultants a consent determination will supersede a determination of legal guardianship because the person with ID/DD is competent in that specific area; this may vary in other states).

**Friendships and Relationships**

An issue that often arises for staff is when they should intervene if two consenting people are being physically affectionate. Our policy states:

Most relationships are not sexual, but some are physically affectionate. All people have the right to be physically affectionate with an agreeable party. Physical affection differs from sex. Sex is the touching of the sexual parts (breasts, vagina, penis, anus) of the body for sexual gratification. Physical affection does not require the ability to provide consent, but rather, just a willing partner.

Therefore if the two people are holding hands or even kissing, the sexual parts are not being touched for sexual gratification and consequently they are being affectionate. Sometimes staff say that the hand holding or kissing might lead to sex. Sometimes yes, but often no. The treatment team needs to evaluate the situation and make a determination.

**Education and Information**

People with ID/DD do need to receive support through education about sexuality, and also may need counseling. They often have not received accurate information from trusted adults, but rather have gotten misinformation from the media and others. At YAI, we provide social/sexual training that includes how to tell the difference between friends, acquaintances, and strangers; numerous boyfriend/girlfriend issues; and numerous topics on having sex. According to our policy, we provide, where applicable:

...education and information depending on interest and need, at a level and pace people with a developmental disability can understand, including the following in this suggested order: Development of self-awareness and self-esteem, awareness of others, body language, assertion, relationships, body changes and awareness, awareness of self as a sexual being, abstinence, sexual expression, awareness of laws relating to sexual expression, avoiding abuse, personal and sexual hygiene, STDs and HIV/AIDS, pregnancy and contraception, marriage, and parenting skills.

**Sexual Expression**

People with ID/DD who live in YAI residential programs and are consenting adults can use their bedrooms when having sexual relations with another consenting adult. It is amazing to me that there are still many agencies that don’t allow this basic human right. If a person cannot use their bedroom, where are they going to go to have sex? Almost any other place could be illegal or dangerous.

We also recognize that people have different sexual orientations and preferences. Stated in our policy is the following: “Accept that people with developmental disabilities may be heterosexual, lesbian, gay, bisexual, transgender, monogamous or not monogamous, and have the right to express themselves accordingly.” As previously stated, staff do not have the right to impose our values. As long as the sexual act is legal and involves consenting adults, we don’t interfere.

**Reproduction and Contraception**

We do address the issues of reproduction and contraception. Most people with ID/DD would have significant difficulties raising a child. Yet there are some people who can. If the person is a consenting adult, he or she has the right to determine a method of contraception if so desired. A person with ID/DD who is a consenting adult and gets pregnant has the legal right in our state to carry the child to term and attempt to raise the child, or to have an abortion, or to give the child up for adoption, and we support those rights. For those who do decide to parent, we offer parenting groups to support them in raising their children.

[Samowitz, continued on page 35]
**Sex, Disability and the DSP: Ethically Supporting Sexual Choices**

by Samuel Arnold and Alexina Vincent-Pennisi

Direct Support Professionals (DSPs) have a rewarding, though at times challenging, role to fulfill. Challenges can be found particularly around support relating to sexuality. Perhaps this is because sex is often still a taboo subject for many people, and because of the contrasting values and beliefs different people have towards sexuality. And perhaps it is also due to the many myths regarding sexuality and disability, such as beliefs that people with disabilities are asexual or are incapable of having an intimate sexual relationship.

In response to this challenge we wish to propose nine general pointers for DSPs to consider about supporting a person’s sexuality and sexual choices. They are based on the premise that for the vast majority of people with a disability, there is very little difference, if any, between sexuality as they experience it and sexuality as experienced by a person without disability. The pointers are as follows:

1. **You don’t have to have all the answers; get to know local support services.** If concerns regarding sexuality arise that are beyond your expertise or knowledge, and cannot be solved through simple education or a supportive conversation, talk with your agency or organization.

As part of the person’s support team you may help to develop strategies to address the person’s sexual support needs as part of their Individual Support Planning (ISP) process. If the person requests and consents to support in this area, in collaboration with your organization a strategy may be to seek out the services of a local sexual health clinic, sex therapist or other health professional. You may be able to locate a professional who specializes in sexuality for people with disabilities. There are also many simple educational materials and pamphlets available. Often providing some information in a format that can be understood is enough to manage difficulties that may arise. There may also be sex education courses that the person is interested in attending.

2. **Be sensitive to other people’s values and beliefs.** Sexuality can be a sensitive subject when there are so many conflicting cultural, religious, and personal differences relating to it. For example, some religions strongly believe in not having sex before marriage. Spend time with the person you support finding out what their beliefs about their own sexuality are. Be aware of your own values and beliefs, and do not impose these on the person you support. If the person’s values and your values are in conflict, then you may not be the appropriate DSP to provide support to the person in this area.

3. **Know whether the person is able to give informed consent for sexual activity.** Sexual relationships need to be consensual. A person needs to know and understand the relevant information in order to make an informed decision. Consent needs to be given freely. A person cannot be pressured to make a decision, and needs to understand the possible consequences for this decision to be considered as valid, informed consent. People need to be of a certain age to give informed consent relating to sexuality, which varies depending on your location. Some people may have or need a legal guardian or conservator who may need to be consulted before providing support relating to sexuality. Talk with your organization if there are concerns about the person’s capacity to give consent, or concerns that a person has been pressured to give consent.

4. **Be aware of ethical guidelines, particularly privacy and confidentiality.** Respect for the privacy and the confidentiality of information in relation to individuals you support are key issues in ethical guidelines for DSPs. For example, if the person you are supporting is an adult, and they tell you something about their sexuality or intimate relationships in confidence, then it is not acceptable for you to share that information with the person’s parents or a colleague unless you have the person’s consent, the person or others are at risk of serious harm, or the guardianship arrangement for the person makes sharing with a guardian appropriate.

5. **Be aware of organizational policies and local laws.** It is first of all important to know the boundaries of your job description and the policies of your organization regarding assisting someone to engage in different kinds of sexual activities. It is also important to know the legal implications for some of the choices the person you are supporting might be faced with. For example, facilitated sex, that is, providing physical support so that a person can engage in sex, may or may not be within the scope of your job description, and may or may not be legal in your state. Possessing certain types of sexually explicit materials may be illegal, and if you facilitate access to an illegal activity, then you could be in trouble with the law as well. It is advised that you consult with your employer regarding your role as a DSP in providing support for specific sexual activities.

6. **Support the development of intimate relationships.** Intimate relationships, for many people, are one of the most rewarding parts of life. For some people with disabilities,
developing an intimate relationship can be more difficult. For example, a person living in a group setting may not be able to invite a partner over for dinner without having to share the kitchen with their co-residents. Some people even have to share their bedroom with a co-resident. You may want to facilitate opportunities for privacy, such as support to have dinner at a restaurant or to go on a holiday, so that the couple can have time to themselves. You may also want to facilitate opportunities to meet new people, which can lead to relationships, such as attending social groups or leisure activities. Many people use online dating, though they may need support to be aware of possible dangers in meeting people online.

7. **Support safe sex.** If a person is engaging in sexual intercourse, you may want to check if the person knows how to have safe sex. For example, you may want to ask, “Do you need me to support you to purchase condoms?” If a person doesn’t know about safe sex, there are many educational materials available to help. You don’t have to teach the person about safe sex if you are not comfortable doing this, but it is important to address this need in the person’s ISP, which may include seeking out support from a sexual health clinic or other health care provider.

8. **Sexual aids can be helpful.** For some people, things like “sex toys” (assistive sexual devices) or sexually explicit literature can be very enjoyable. For a few people with certain types of physical disability, using a sex toy may be one of the few ways that they can enjoy sex. If your job description, agency policies, and local laws allow, you may be asked to support a person to purchase materials or sex toys. A person may need to be taught about the appropriateness of some activities, such showing explicit materials or sex toys to others. They may additionally need education about safe and hygienic use of sex toys; if a person needs such sexual education, ways to address this need should be identified through the Individual Support Planning process.

9. **Sexual health checks are just as important for people with disabilities.** Remember that regular pap smears, mammograms, and testicular checks are just as important for people with disabilities as they are for people without disabilities. It is important that these checks are part of a person’s regular health exams. If their current health care professional is unwilling or unable to provide such checks (for example, some health care providers may be unfamiliar with strategies for giving mammograms or pelvic exams to women with certain types of disabilities) you may need to help to advocate for the person and may be asked to work with their care team to connect the person with a health care provider who can provide these exams.

Finally, remember that most people with disabilities enjoy sexual activity and will start to develop their own sexuality at the same chronological age as people without disabilities. Sexuality will continue to develop over the course of the person’s lifespan and will be as diverse and colorful as it is for any other person in the community. Knowing that a person is enjoying their sexuality or a healthy intimate relationship can be very rewarding, particularly if you have been part of supporting this to be a possibility.

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Where to begin? How do we have this conversation? Sitting at the round glass dining room table with my mom, Nancy, and a laptop, we talk about the process, the road that we travel on together. She brings out her notes and she says, “I wrote something” and proceeds to read a beautiful summary of her experience raising a girl with a disability, who just happens to be a lesbian. Or should I say a Lesbian who just happens to have Cerebral Palsy. We begin with her gut reaction to my coming out… “At first, I was very surprised! What about those yummy Brad Pitt posters on the bedroom wall, or the tears and screams for hot male rock stars?” She goes on, “So very pretty, feminine, and even a flirtatious side; kisses and college sex.”

The conversation continues and she goes on to say, “But when the truth came out I started to put the pieces together… The pain and frustration I remember her suffering so, not a poor me over a disability, but more confusion and devastation over losses of best girlfriends. The lack of support in her world, and how to talk about something so strong you were feeling. Where do you turn when you don’t want to let down your family? Oh, how I wish I would have seen the signs earlier, opened the door for a conversation. We knew gay guys but not so many lesbians. Corbett expressed that she thought only guys could be gay.”

With tears streaming down my face, I say, “You did know what I was going through!” We laugh now, but when you are in it, it feels like nobody sees you. I had tried to get involved and interact with my peers, but all they saw was my wheelchair, the Disability. I was at a party once, the only boy/girl party I was invited to before I was completely left out, and I remember a boy whispering, “How do you dance with her?” My heart broke. This is only one obstacle, but it represents the distance between me and the opportunities that others, without disabilities, may experience. I might have had the chance to “figure things out” had I had a way or opportunity to navigate those social/physical gaps. How do I help others to be comfortable around me when I am still figuring what I am comfortable with myself? There is a period of time that young adults use to flirt, experiment, make mistakes and learn from; this period did not truly happen for me until I went to college.

In trying to help me, I was put into counseling from the time I was seven years old until my fourth year of college. Although I had several counselors, it seemed to always be about the disability and my adjustment to it rather than the deeper issue. What if someone had taken the time to understand that the real issues I was having had to do with understanding who I was as a sexually-maturing woman who had some real questions about what all these feelings meant? What if I had gotten some validation, someone had seen that the struggle wasn’t disability-related but sexuality, wanting relationships, intimacy, sex to find what feels good and what doesn’t? What if someone understood that I wasn’t getting my human needs met? My mom goes on to read, “A part of me was worried: she is so sexual, what is going to happen to her?” And my response is, “It was so painful because I had all of those feelings and had no place to put them. Everyone asked if I was angry because I was disabled and I was angry, yes, but it was...
about wanting intimacy. I wanted the movie stuff. I wanted the Tom Cruise Risky Business stuff.”

So it was in college where I met peers who saw me for me and I was able to have those experiences I saw in the movies. I was searching for and wanted to give normalcy to a very not normal situation. Then I met my Ashley and it was like finding that one thing that brings you comfort. Then the feelings of doubt set in. I felt as if I let the family down. I had always envisioned bringing home a boyfriend to give my brother a male role model. Instead, I brought home Ashley. My mom explains, “Suddenly I was at a loss for rules. Should she sleep with her friend in my house? I wouldn’t want it if it was a guy. I laugh about the tent built in her bedroom.” She goes on, “My role changed so. I no longer helped with those special needs – dressing, bathroom etc. Felt left out. But then I’d hear them laughing and talking, talking so at ease with each other and very much in love. Questions pop into mind like, ‘What about babies?’ As time went by and their relationship grew it was the same letting go as it would be in any loving relationship. Their comfort level slowly let me back in. I found myself so happy that they were so happy. It’s okay not to be immersed in their life. Everyone grows.”

We discuss that mom was unsure about some of the literature Ashley and I gave her – information about Parents and Friends of Lesbians and Gays (PFLAG) and books. She mentions, “I thought it was about people who are upset about their gay kids.” Both of us realize now that this was my way of asking her to show me acceptance and support. My mom sums it up when she says, “Gay is this world of wanting rights and being supported. I could have joined something to show my support, even though I was supportive. It amazes me, all the derogatory comments made by people all the time. It is disgusting how freely people discriminate.”

We want to leave you with the understanding that it’s not always about disability. Support comes in all shapes, sizes, and needs to be recognizable by the receiver as well as the giver. Laughter through tears is the best way to get to know yourself and others. Even when the lines of communication look thread bare, keep talking; there is always someone on the other end. Information is vital to understanding the real issues, and sometimes the issues just need a voice.

My mom and I have learned so much about each other and ourselves by writing this article and we encourage people with disabilities, their families, friends, and professionals to support the fact that people with disabilities have the right and desire to express their sexuality, experiment, experience, fall in love, make mistakes, get a broken heart and dream just like everyone else. May we all find happiness where we least expect it.

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DSPs Talk About Supporting GLBT Individuals

The Impact editors recently asked Direct Support Professionals (DSPs) to share the most important lesson they’ve learned about supporting the sexual choices and privacy of the individuals with disabilities with whom they work. Among the responses were these about supporting individuals who are gay, lesbian, bisexual, and transgender (GLBT):

- Years ago, a team’s advocacy prompted Jim’s group home to allow him to interact intimately with Tina. But Jim’s interest in Tina didn’t last. Now years later, Jim’s own self-advocacy has resulted in his long-term romance with Tim. The guys love spending time together in each other’s rooms. But for their housemates, “It’s just no big deal.” - Marianne

- I actually learned acceptance and support of sexual orientation at the age of 12 when my sister Joan informed me she was gay. I remember telling my friends it was the same as a man loving a woman. It never occurred to me to judge her, or anyone else. So when I started my job in home health-care 15 years ago, respect, support, and privacy for individuals, no matter who they are or what their disability is, was already there before I walked through their door. An exuberance of a non-judgmental stance, of genuine compassion, helps my consumers feel comfortable, and me, approachable, with anything they choose to share. I don’t ask a consumer what their sexual orientation is; that is inappropriate and not part of a DSP’s job. Privacy isn’t a choice, it’s a right. So one of the greatest lessons for me would be to treat every consumer with intellectual and developmental disabilities with the same respect, support, acceptance, dignity, and right to privacy as I would treat any other consumer. And that began with my sister Joan. — Pamela

- I worked with a young woman who liked to dress in boy’s clothes and was attracted to other females. Staff did not accept who she was. I took her to Philadelphia’s Outfest, a family-friendly gay pride event. She could not stop talking about the women who looked like her. I learned that we have to find ways to affirm not only heterosexuality, but all sexuality and forms of gender expression. — Jennifer
A Witness to Courage

by Dave Hingsburger

“Can we talk to you after the conference?” Public speakers hate this question. It means that someone wants us to sit and do a free consultation after we have spent an entire day in front of an audience. Few seem to realize that public speaking takes a lot of energy and at the end of a day all that is wanted is beer and bed.

Here my initial assessment was wrong. A small group of very nervous people gathered to ask me what I was doing the next day. They knew, they said, that I was staying over Saturday and flying home Sunday, and they wanted to take me somewhere. Right after presenting “prosex attitudes” in a state wherein agencies had an almost universally hostile practise towards sexuality and disability, they wanted me to get in a car with a bunch of them. I said that I was uncomfortable with the idea as they were all strangers to me and I could tell by their behaviour that something was up. They said they were just excited and really wanted me to come. To their credit they didn’t pressure me, and just said, “We’ll come by tomorrow morning at 10:00. If you decide then you don’t want to come we will just drop it.” I agreed.

The next morning I went outside the hotel to watch for them. When they drove up in a vehicle with an agency logo on it, I made my decision. I’d go. It seemed to me that it would take an awful lot of coordination to arrange for an agency car to abduct a harmless Canadian. I got in and we drove for almost an hour. I enjoyed chatting with them and I felt buoyed along by their excitement. We crossed a state line and I asked why we were leaving the state. They said, “Just wait.”

We entered a smallish city and in moments were pulling into the parking lot of a Unitarian church. I went in with them and saw several people, many who had been at the conference the day before, rushing about decorating the sanctuary. Clearly I had come to a church where a wedding was about to be performed. I sat near the back with the group with whom I had travelled. When the music began the small crowd of about 50 hushed, an air of expectancy – no, reverence – filled the room. Then into the sanctuary, into the house of God, came a man with a developmental disability. He walked slowly, his gait that of one who had once worn the shackles of institutionalization. He looked to be near 60. I smiled, tears formed in my eyes. When I see people with disabilities marry, I recognize that the march to the altar to stand before God is long. They must march past societal bigotry, family disapproval, religious intolerance, and agency dictates. He finally reached the altar. The music stopped. Silence. The music began again.

From the other door came another man. He too was older. He too walked as if the chains that bound his feet had only recently vanished. I looked at the woman next to me and said, “What’s going on?!” She smiled and said, “They are finally getting married.” She continued by telling me that they had met as young men in the state institution and had been caught together “engaging in sexual behaviours” (social worker for “making love”). They had endured years of punishment and separation. A staff member heard the story from one of the men and diligently set out to reunite them. When she found the other man living in a group home operated by the same agency in a different town, nothing could stop her. They would live together if they chose.

When they were reunited, they decided that they would not live together, they would not have sex, until they were married. They had been punished so often, told continuously that they were dirty, sinful, hateful creatures, that they needed to get married “like other people.” When they were told that they couldn’t get married, they cried but had seemed prepared for that answer. The staff member wouldn’t let go of it. She visited a Unitarian church in their town and worked with the minister to find a church out of state where a ceremony could be performed. She felt that this would be far enough removed to protect the sanctity of the ceremony and provide the secrecy that was needed. Everyone there had pledged support and secrecy.

The two were informed that a marriage could be performed. The staff told them that while God might smile on the marriage, the government wouldn’t. It would be a holy ceremony, not a legal contract. That was fine with them, they said, seemingly unconcerned that we in the modern world had switched allegiances and granted governments more power than God ever wanted.

“See the fellow on the right?” I nodded while noting the man who had walked in first. “When he was in the institution, he was castrated. They thought that would stop him from being homosexual and wanting to see his boyfriend. Can you believe it?” I can and did, having worked with two women with disabilities who had been clitorectomized to stop them from being sexual. How we hate the hearts of people with disabilities! We have caged their bodies, disfigured their genitals, drugged their thoughts. But we have never, ever captured their hearts or controlled their

They had been punished so often, told continuously that they were dirty, sinful, hateful creatures, that they needed to get married “like other people.”
The two men stood and pledged their lives to each other. They stood on holy ground and each professed, through their pledge, a faith in each other. Seeing the beauty and steadfastness of human love and the power of the human spirit, I wept. And, I believe, so did God.

**Sexuality Education Resources**

- **Sexuality Education for Children and Adolescents with Developmental Disabilities: An Instructional Manual for Parents or Caregivers of Individuals with Developmental Disabilities** (http://www.albany.edu/aging/IDD/docs.htm). By D. Baxley and A. Zendell. This manual, available online for free, is designed to help parents and caregivers assist young people with intellectual or developmental disabilities in their exploration of self and sexuality, preparing the young person to live and participate as independently and safely as possible in the community as an adult. Among topics covered are bodily changes, social skills, dating, and recognizing and avoiding abuse, as well as tips for adapting the material for different learning styles. Published by the Florida Developmental Disabilities Council, Inc. Also available is a companion manual for educators.

- **Sexuality: Your Sons and Daughters with Intellectual Disabilities**. By K. Melberg Schwier & D. Hingsburger. This book for parents talks about how to interact with children — no matter their age or ability — in a way that increases self-esteem, encourages appropriate behavior, empowers them to recognize and respond to abuse, and enables them to develop lifelong relationships. It includes stories, advice and practical strategies from parents, as well as individuals with intellectual disabilities explaining what’s important to them. Published by Brookes Publishing Co. (see http://www.brookespublishing.com, 800/638-3775).


- **Circles® Curriculum**. Co-created by L. Walker-Hirsch. The Circles® Curriculum is designed for use with students who have intellectual and developmental disabilities. It teaches relationship boundaries and relationship-specific behaviors using a simple multi-layer circle diagram to demonstrate the different relationship levels students will encounter in daily life. It’s composed of four different programs that also cover how to apply the rules of social intimacy in more complex settings, how to recognize and avoid sexually threatening or abusive situations, and how to prevent and treat communicable and sexually-transmitted diseases. Available from James Stanfield Co. Inc. (see http://www.stanfield.com/circles-main.html, 800/421-6534).

- **Sexuality Training for Individuals and Agencies**. Agencies looking for workshops on sexuality for the adults with disabilities they serve, and for their staff, may find that the Centers for Independent Living (CILs) in their area have this resource available. To locate nearby CILs contact the National Council on Independent Living at http://www.ncil.org/ or call 877/525-3400.

- **You’ve Got a Friend: Supporting Family Connections, Friends, Love, and the Pursuit of Happiness**. The College of Direct Support, an online, competency-based training program for Direct Support Professionals (DSPs) nationwide includes among its courses “You’ve Got a Friend...,” which explores the importance and meaning of relationships in the lives of people of all ages with disabilities. Topics covered are the benefits that healthy relationships bring to people’s lives, common perceptions and prejudices about people with disabilities that create barriers to social relationships, common challenges that DSPs face when supporting people in developing and maintaining relationships, strategies for overcoming these challenges, and effectively supporting family relationships. To learn more visit http://www.collegeofdirectsupport.com and under “Curriculum” select “CDS Courses.”
People with disabilities want to get married. We fall in love and want to make a commitment to the person that we love and become a family. For many it is a religious choice to get married. Yet, too many people with disabilities must choose between getting married and continuing to receive the benefits they need to live from federal programs such as Supplemental Security Income (SSI) and Medicaid. Too many have to struggle with this choice because of “marriage penalties.”

The Problem
SSI is a needs-based federal program that helps people with disabilities (as well as people who are elderly) who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter. If two people receiving SSI get married, they will receive 25% less in benefits than they did as two individuals. The theory is that a couple can live on less income together than they would as individuals. In addition, even if a couple doesn’t get legally married, they can be considered to be “holding out” if they are presenting themselves as a couple by SSI definition; for them, the same rules apply as for a married couple and they will have their benefits reduced. If only one person in the couple is receiving SSI, the benefit will still be reduced or they may no longer be eligible for it. In addition, there is also a resource limit; the amount of money you can have in the bank for an individual is $2,000 and for a couple it is only $3,000. Beyond these marriage-related SSI benefit and asset restrictions, eligibility for SSI in most states means eligibility for Medicaid. Medicaid covers services not covered by other health insurance plans such as a personal care aid, certain durable medical equipment, medications, and transportation to medical appointments. So anything affecting SSI eligibility may have a ripple effect. (For more information see Treatment of Married Couples in the SSI Program on the Social Security Administration Web site at \[\text{http://www.socialsecurity.gov/policy/docs/issueterminerates/1000501150}].

Obviously, loss of SSI or Medicaid benefits can be devastating, life changing, and even life threatening to a person with disabilities. And that is why there is a national movement to get this changed. I want to share with you how marriage penalties are affecting real people, and why we want them changed, by sharing the perspectives of two other self-advocates: Timothy and Kurtlyn.

Too many people with disabilities must choose between getting married and continuing to receive the benefits they need to live.

Too many people with disabilities must choose between getting married and continuing to receive the benefits they need to live.

Timothy’s Story
I was diagnosed with Duchenne Muscular Dystrophy at age three. At almost age 37 I am on a ventilator 24/7 and can only turn my head a little and move my fingers slightly. Having a pre-existing condition and high medical bills, the only way to receive the care I need is through Medicaid, and it is the same for many with permanent disabilities.

I had a girlfriend a few years ago and it didn’t work out, but I wonder about the future if I meet someone again. Let’s say I got married and our joint assets are more than $3,000. I would lose my Medicaid benefits. Then, with my nursing costs alone being more than $300,00 a year our assets would go below $3,000 in a matter of months as we spent them down, and I could go back on Medicaid. During this process my spouse would probably have to take a pay cut or quit her job altogether to ensure we keep our assets below $3,000. Think for a moment what we might then need. Off the top of my head I come up with housing assistance, food stamps, and Medicaid or Medical Assistance for my spouse and for any children. Without the Medicaid loss, my spouse would have probably taken care of all of the above and more instead of the government. People with disabilities on Medicaid who get married and cannot stay on Medicaid do save the Medicaid program some money, but they cost other government programs more.

The Medicaid Marriage Penalty is misdirected and wrong because it prevents many people with disabilities from getting married or even staying married. People with disabilities deserve to be able to get married to the one they love. Some believe the only way to be with the one they love is through marriage. If you believe people with disabilities should be able to get married, please go to my Web site (\[\text{http://DisabilityVoiceSpace.org}\]) to learn more about the Medicaid Marriage Penalty (you can find it under “Advocacy”), and sign the online petition. Please don’t forget to tell everyone about this including your legislators!

Kurtlyn’s Story
I would like to see people who receive SSI or SSDI not be affected by their spouse’s income. It is not anyone’s fault that they’re disabled, and therefore they should not be treated as such. Some disabilities have tremendous care involved, which can be financially straining. To
lose the financial help of Social Security is just wrong.

I receive Social Security disability benefits due to my mental illness. Because of my mental illness, I am limited to part-time work. It is not my fault that I have my mental illness, and I have to struggle financially as it is because of not being able to work full time. If I were to get married, I would not want to be a financial burden on my husband because I lost my Social Security. It is hard enough now as it is with me supporting myself. And I don’t want to have to be in the position where I have to choose between keeping my benefits or getting married.

People with disabilities should have the same rights as anyone else, and that should include marriage. People with disabilities fall in love, and have the same beliefs as those without disabilities when it comes to making the commitment to spend the rest of their lives with someone. Marriage is a very important thing to a lot of people, and I don’t want to have to miss out on it just because of the risk of losing my benefits. I also don’t want to have to lose someone in my life out of fear of me being a financial burden to them.

I would like to see people who receive Social Security in any form be able to keep their benefits if they get married. I cannot imagine losing my Social Security, which would then make me lose my insurance as a result. I have to go to counseling once a week, and there are times where I go twice. There are also times where I participate in groups (another service that is billed), or my doctor’s visits; all these things add up as a financial responsibility that I don’t want my spouse to have to take on just because I have an illness. I cannot afford to lose my insurance just because I lost my benefits for marrying someone. There have also been a few times where I had to take a leave of absence as a result of my symptoms increasing. I rely on my Social Security to fall back on when I am out of work. Please take into consideration the stress someone with disabilities has to go through to begin with to get through a day. And once again, having a disability is not someone’s fault.

**My Story**

Nine years ago my mother said to me, “I want you to find someone, fall in love, be happy, and someday get married.” I was aware of some of the problems with her request, including federal marriage penalties, and I felt: Why try? It’s never going to happen so just give up.

But, today I am married to the most patient, wonderful, and understanding woman in the world. When I started to date my wife I had no idea I would marry her. I honestly figured that we would just date and that would be that. I am a self-advocacy coordinator who works with people with disabilities. I am also a trainer. My wife took part in training to get ready for a new job as a service coordinator and there was a problem with one of the trainers and their equipment. I happened to be there and Amber came up to try and help me figure it out. When we looked at each other we knew there was something between the two of us. We weren’t sure what, so for the next three days of training we talked and had lunch every day. She thought that I wanted her to work for me as my service coordinator, but of course I had other designs for our relationship. There came a time where I was e-mailing, calling, trying to convince Amber to date me. For a little while the calls stopped. So I kind of figured she’d found a boyfriend. I finally contacted her again and she gave in and we went on a date. She took me to her church. Our first real date, outside of church, was a New Year’s Eve party where I had the opportunity to give her the first kiss in our relationship. She took me home to my place, and when we got there I showed her a photo album. In the photo album was a picture of this little kid (me) at camp for “crippled and disadvantaged children.” She started to cry and said, “You’re little Billy!” You see, she went to a neighboring camp, Camp Pioneer, as a child at the same time as me, and the campers from Camp Pioneer got to come over and visit the camp where I was. She saw me sitting at the baseball diamond, wanted to find out more about me, and wanted to just play ball with me. We had actually met 30 years earlier.

When we started to think about getting married we began looking into how I could be married and keep my Medicaid that I need for a personal care aid and medical equipment not covered by regular health insurance. I did not want to put financial pressure onto Amber so I applied for Medicaid through the Medicaid Buy-in for Working People with Disabilities. I can keep my Medicaid as long as our income does not exceed $73,884. My wife still had to fill out a spousal refusal form that states she refuses to be responsible for the financial expenses for my personal care aid and the medical equipment. Some readers might be saying to themselves that sounds a little harsh, but when you consider how much personal care costs per year you would realize that we would not be able to cover the cost with our earnings, so this was the only way to go.

Today, I am truly lucky to have a job where I make enough money that I do not have to worry about SSI benefits. But, many other people with disabilities are not in my position. That’s why I’m working with others to try to eliminate the marriage penalties for SSI and Medicaid. I believe that by removing the penalties, the number of people on SSI who marry will increase. This will allow more people with disabilities who have found someone with whom they want to spend their lives to actually be happy and not have to worry about how they are going to be able to live. Please join us in making that happen!

**Note:** I would like to say thank you to the Self-Advocacy Association of New York State and the SSI Marriage Penalty Task Force for their tireless support and efforts to remove the marriage penalties. Also, thank you to my friends who allowed me to share their stories.

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Eighteen Years and Counting: 
Tom and Maureen’s Story

On June 27, 2010, Tom and Maureen Marolt marked their 18th anniversary. In July they sat down with Beth Fondell and Vicki Gaylord of the Institute on Community Integration to talk about their journey together through love and life.

Q: Maureen, can you tell us where you met?
Maureen: We met on a blind date. A mutual friend fixed us up. I was living at Clara Dora Residence [an ICF-MR], and I was working at Opportunity Workshop. The friend said there’s this guy I want you to meet. I was kind of leery at first. She brought him to the lunch room and he sat down. He imitated W.C. Fields and then Mae West. His first line was...Do you remember what you said, as W.C. Fields?
Tom: Yes indeed my little chickadee. Yes indeed, yes indeed.
Maureen: [laughter]. And then he did a Mae West impression...
Tom: Come up and see me sometime.
Maureen: [laughter]. He had me rolling on the floor and I knew from that point on he was the guy for me.

Q: How long did you date before you got married?
Tom: 16 years.

Maureen: We met in the summer of 1977 and at the time dating between kids with disabilities was kind of unheard of because the guys were separated from the girls. People thought that people with disabilities should not date. But we are human.

Q: Did people say things to you to discourage you from dating?
Maureen: Counselors gave you a look.

Q: How did your families feel?
Maureen: First, they weren’t real pleased. Well, I think they were afraid of the fact that he had seizures, so they thought financially we would not be able to support ourselves.

Q: Did your family like Tom?
Maureen: First, my grandmother met him and thought he was okay. She said if she was 20 years younger she would have...[laughter].

Q: And other family members?
Maureen: Tom made the mistake of discussing politics with my father. My dad at that time was the mayor of my hometown.

Q: So there you are, Tom, this young guy dating the mayor’s daughter, discussing politics with him. Did you think that was a good move?
Tom: [laughter]. He was the one that liked to talk politics. Then I don’t know how I got into it.

Q: Tom, what did your family think about Maureen?
Tom: My dad had died on May 15, so she didn’t get a chance to meet him. When he was alive I asked if I could bring her up for him to meet, and he said, “Yeah, that’s cool.” But then he died. When the funeral and everything was over, I later called up my mom and asked, “Is it still okay to bring Maureen up?” And she said, “It’s okay,” so I brought Maureen up and they hit it off really good. My brother, Don, used to play football for the Mesabi Junior College, and one year I asked Maureen if she wanted to go to the game. So that’s where she met Don, and he liked her.

Q: I’m wondering what you saw in each other that made you think he’d make a good husband or she’d make a good wife?
Maureen: Well, in Tom I could see he was hard-working, and he made me laugh. The laughter keeps us together. You have to laugh at each other once in awhile. And I knew that he would be a good provider.

Tom: She cooks really good and I like her cooking. She works hard also. I’ve seen her at work and she works really hard. I don’t know how she does it. Then every once in awhile she’ll say, “Let’s take a break and go out somewhere,” and then we’ll come back home and relax and joke around. She’s all around a good wife.

Q: One of the things I’ve noticed about you over the years is that you’re very thoughtful about each other, very considerate.
Maureen: Yes, we are very thoughtful toward each other. That’s important.
Tom: Yes, it is.

Q: I’d like to hear more about the marriage proposal.
Tom: It was on St. Patrick’s Day, and we were out somewhere and I said, “Mo, how’d you like to marry me?” And she got this big glow and said, “Okay.”

Maureen: He gave me this cocktail ring, a green stone with stars around it.

Tom: Do you still have that? How come you don’t wear it?

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Maureen: He gave me this cocktail ring, a green stone with stars around it.

Tom: Do you still have that? How come you don’t wear it?
Maureen: And then later we got our gold wedding bands.

Q: Who were the people who supported you to get married?
Tom: My mom of course, and my brothers, my sister, our pastor at St. Richards Catholic Church, some people at the Arc.

Q: Who helped you with the arrangements or did you do it all yourself?
Maureen: My older sister went to my parents, and kind of went to bat for me. She said, “Dad and mom, she’s ready to get married.” At first they didn’t want to let me go. But I had a lot of good support. My aunt, Sal, was very supportive, and my counselor at Arc was very helpful. We had premarital counseling through Arc, it was a program for about 8 weeks. Also at St. Richard’s we worked with the wedding coordinator. I have a friend who owned Mary Kay Bridals, and she got me my dress.

Q: Did you have any attendants?
Maureen: My best friend, who was one of my roommates, she stood up for me. And then another friend was my maid of honor. I didn’t want to play the favorite sister game. I have five sisters and I didn’t pick any of them because I didn’t want anyone to be left out and feel bad if I didn’t choose them. So Tom and I tried to involve as many people with disabilities as we could in the wedding.

Q: And who stood up with you, Tom?
Tom: There was my brother, my sister, two of my buddies that I grew up with, they stood up. And my mom was there.

Q: Who were the people who supported you to get married?
Tom: We sent out about 80 invitations and 75 actually came. We figured not too many would come because, you know, they’re getting up there in age. But it was a beautiful day. One thing she forgot was to throw her bouquet. No one gave her a cue to do that.

Maureen: I thought with five sisters one would give me the cue. Eventually as we were leaving the reception to go to the hotel I did throw it and I believe my sister Sheila caught it.

Q: Tom, anything else stand out about the wedding day?
Tom: I think, correct me if I’m wrong, that a friend used to drive limousines so he drove us to the hotel in the limousine. That night I didn’t know what got into me. At the reception everyone was asking if I was okay; they said I looked flushed. I felt okay. Of course I’d never been married so it must have been nerves.

Q: What do you like most about being married?
Maureen: We take the good with the bad. We’ve had our ups and our downs. It’s give and it’s take. But I’m so happy we’ve made it this far. We had a tough patch where it was rough. There were times when he was out of a job and a lot of times he would get frustrated.

Q: Tom, for you what’s the best part of being married?
Tom: For me the best part is you can count on each other. Whereas if you’re single, you’re the only one you can count on. So it’s nice that you can have somebody to come home to or talk to if you’re tired.

Q: When you look back on your wedding day, what stands out most?
Maureen: The thing that stands out most is that both parents walked me down the aisle and did it to the prelude from the Sound of Music.

Q: When you look back on your wedding day, what stands out most?
Tom: We went with a group called Off the Beaten Path. They give tours with people with special needs. What happened was the first time I went to Hawaii, after I came back she saw the photos and said, “Man I’d love to go there sometime.” So we went and had a good time. She wants to go back.

Q: For your 17th anniversary, what was really special. What did you do?
Maureen: That was Maui.

Tom: We went with a group called Off the Beaten Path. They give tours with people with special needs. What happened was the first time I went to Hawaii, after I came back she saw the photos and said, “Man I’d love to go there sometime.” So we went and had a good time. She wants to go back.

Q: Just about a month ago was your 18th anniversary. Did you do something special?

Maureen: In the morning I took him golfing, and then that afternoon our friends took us up to Stillwater to a German restaurant.

Tom: I did plan something for that night, but that didn’t work out so some friends of ours took us to Stillwater to that restaurant.

Q: Anything you want to say about what you’ve learned from 18 years of marriage?
Maureen: You have to give and take, and take the good with the bad, and you work through difficult periods. In our difficult period we asked for help.

Tom: I want to let people know that it takes a lot of hard work and I think communication’s number one, and making sure you’re both right for each other in the first place.

Q: You haven’t said too much about love. Are you still in love?
Both: Oh yeah!
Maureen: Yes, we do love each other and very, very much.

Note: Wedding photo by Dale Studios, Eden Prairie, Minnesota

Tom and Maureen live in St. Louis Park, Minnesota. She works at PetSmart, and he at the new home of the Minnesota Twins, Target Field in Minneapolis. When they’re not working they volunteer for a number of community organizations, go to sporting events, golf, bowl, and work on their condo.
As a woman with a disability, I don’t always anticipate every choice I make to be difficult and challenging. Actually, I see a lot of things in my life as easy and simple because of how I choose to live my life as a disabled woman. Most people with disabilities will tell you that we want to be treated in the same way as everyone else. We want the same chance to be able to live our lives. This is true for me, too. My disability isn’t the main anchor in my life from which all other things stem. I define myself as disabled, and yes, it does impact how I live my life. However, I don’t make decisions for myself strategically around the fact that I have a disability. I took the same approach to pregnancy and motherhood as I have done with most things in my life, by making good decisions and just letting things happen by themselves.

He was just so perfect and beautiful when I first saw him. The first thought that came to me was, “This baby is way too cute to be mine. They must have switched him at birth!”

For me, getting pregnant was not planned. I did it the old fashioned way. There were no visits to the doctor, no exams, no specialists. I never got to ask the question, “As a woman with a disability, am I able to have a child?” That question pretty much got answered for me. At first, I was extremely excited. Then, I started asking myself questions about how things would go for me during the next nine months. Was I scared? Yes. Not because I was a pregnant woman with a disability. My concerns were just the regular fears, worries, and stress that any expectant mother would have.

Everything was going well during the first six months. I was eating well, the baby was healthy, and I was expected to carry to full term. During one visit to the OB/GYN, however, it was discovered that I had high blood pressure. My bottom number was extremely high and I was told this could affect the baby’s heart rate by slowing it down. The clinic staff whisked me away and admitted me into the hospital promptly for further monitoring. Fortunately, the baby’s heartbeat was strong, so my blood pressure was not affecting him. After lying down for a couple hours, my numbers returned to normal and I was able to leave the hospital. I continued to have blood pressure issues throughout the rest of my pregnancy. I was admitted about three to four additional times until I had my son.

My doctor sent me to a perinatal specialist for my blood pressure issues. He said because I had polio and have no use of my legs, my body was compensating for being pregnant by increasing my blood pressure. He also said that this was very common for pregnant women with paralysis from the waist down. He recommended that I not carry to full term but have a scheduled C-section at about 35 weeks. He said that going into labor and delivering the baby naturally might increase my heart rate too high and put the baby or myself at risk. I would be put under general anesthesia for the C-section. After hearing all this, I again sort of just continued on with my mantra of letting things happen by themselves. The specialist gave me a more high powered ultrasound of the baby and the results were very good. The baby was doing just fine, which helped put my mind at ease. Physically, the last three months of pregnancy were very difficult. To make matters worse, my glucose test determined that I also had gestational diabetes. From that point on, I had to check my blood sugar level before each meal. I ended up seeing two different doctors twice a week. I was also getting big and moving around became difficult. I could not transfer easily out of my chair any longer. My husband had to drive me to work every day because I was not able to get in and out of my car. I was pretty miserable.

In the end, it all worked out fine. Two days before the C-section, I underwent an amniocentesis to make sure the baby’s lungs were developed enough to be delivered. The results of the test were good, which meant the C-section would proceed as planned. Surgery was scheduled at 9:00 a.m. on January 28, 2009. My son, Matthew was delivered at 9:53 a.m. He weighed 5 pounds, 8 ounces. I woke up in the hospital room, struggled to keep my eyes open after all the anesthesia, and only managed to do so because I wanted to see my baby so badly. He was just so perfect.
and beautiful when I first saw him. The first thought that came to me was, “This baby is way too cute to be mine. They must have switched him at birth!”

All in all, pregnancy was not too bad. Being totally asleep during delivery seemed to be a breeze, really. I didn’t have to do anything! After all the excitement with pregnancy, the C-section and the hospital, it occurred to me that the real hard part was just beginning as we brought Matthew home. I thought about the months to come when Matthew was a newborn. I wondered how I would be as a mother and if I would “perform” up to par with non-disabled moms. I thought even further ahead and wondered how I would handle things when he began to walk and run and what I would do if I couldn’t keep up with him. Would other kids tease him in school about having a disabled mom? So many things went through my head.

In the beginning it truly was easy because he was so tiny. Wheelchair users usually require support when picking things up, especially if it’s heavy. But Matthew was so light that it didn’t require a lot of effort. It’s when he became heavier that support became an issue. Using the edge of a bassinet or crib to support my torso works well when both hands are being used. Luckily, my hand dexterity is good and I have never dropped him, which is more than some able-bodied moms can say. There are lots of other logistical things to consider when a baby comes into your life, but I guess that’s just what happens whether you have a disability or not.

The truth is, babies are really smart, resilient, understanding, and loving. If you show your love, respect, and support to them, they will do the same for you. Granted, he is only 18 months old, but Matthew “gets” that mom is different. He knows that I use a wheelchair, and to him it’s not a big deal. When he wants to be picked up, he will climb up on my footrests and I’ll pick him up. If he wants to show me something and he is up the hill in the backyard, he will come down the hill and show it to me. He has it figured out more than I do! I think when he was about six months old I told myself that I would allow him to be the person he wants to be without letting the insecurities I have about my disability get in the way. Matthew seems to be fine with everything so far, so instead of worrying about him growing up as a little boy with a mother who has a disability, I’m going to just focus on him growing up as a little boy. I’m back to going with the flow again.

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Parenting as a right for individuals with intellectual disabilities is a relatively new concept. In the last 40 years, there has been a paradigm shift in attitudes and practices toward individuals with intellectual disabilities who desire to be parents. Today, the most significant aspect of the national conversation about adults with intellectual disabilities who are or desire to be parents is that self-advocates, advocates, court personnel, policymakers, researchers, Guardians ad Litem and concerned members of the community are actually having that conversation about such a right. Several historical events have brought us to this new place.

New Ways of Thinking About Parents with Intellectual Disabilities

by Bernadette Irwin

Parenting as a right for individuals with intellectual disabilities is a relatively new concept. Parenting as a right for individuals with intellectual disabilities is a relatively new concept. Parenting as a right for individuals with intellectual disabilities is a relatively new concept. Parenting as a right for individuals with intellectual disabilities is a relatively new concept.
discrimination, and to render “appropriate assistance” to persons with disabilities, including parents with intellectual and other developmental disabilities under Article 23. This Article states that signatories “shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.”

An additional milestone in the paradigm shift regarding parents with intellectual disabilities occurred as the result of a two-day planning retreat in 2009 in which 12 individuals from Canada and several U.S. states came together to develop a strategic plan to formally address the needs of parents with intellectual disabilities. This meeting resulted in the founding of The Association for Successful Parenting: Enhancing the Lives of Families When Parents Have Learning Difficulties (TASP). During the retreat, the participants developed TASP’s Mission Statement (The Association for Successful Parenting, 2009):

We are dedicated to enhancing the well-being of at-risk parents with learning difficulties and their children. This primarily includes parents who may be identified as persons with intellectual disabilities or borderline intellectual functioning.

It also created the following Guiding Principles of TASP:

• We recognize that family life is complex.
• We move forward in step with self-advocates in this shared work.
• We acknowledge that all families need support and rely on inter-dependent networks.
• We accept that separation from parents is sometimes in the best interest of children.
• We believe that our expertise and resources may also benefit parents with other cognitive challenges and the people that support them.

TASP has also identified the following as the practices it uses in its work:

• Facilitating community partnerships and networking.
• Offering educational opportunities.
• Engaging in advocacy and ongoing system change to achieve social justice.
• Partnering with self-advocates to promote self-determination.
• Promoting evidence-based parenting skill assessments.
• Developing and endorsing evidence-based curricula for training.
• Honoring family autonomy, self-determination and parent strengths.
• Encouraging natural supports, community acceptance and inclusion.
• Developing individualized supports that utilize evidence-based practices.
• Consulting with partners in child welfare, early intervention, education, health care, disability services and family support.
• Working within interdisciplinary teams to individualize services.
• Establishing and raising quality standards in assessment, training, service and research.
• Promoting and conducting research.

Advocacy for the rights of individuals with intellectual disabilities with regard to parenting appears to have reached a critical mass. Local, state, national, and international organizations and agencies are addressing the needs and challenges of parents with intellectual disabilities. Public and private health care, education, housing, welfare, vocational, mental health and other social services, child and adult protective services, and the juvenile and adult court systems are beginning to recognize the need for coordinated, comprehensive and sustained services for these parents and their children. So, in 2010, as we are in the midst of a paradigm shift regarding parents with intellectual disabilities, where can people go to learn more about the emerging practice of supporting parents with intellectual disabilities? Here are some suggestions:

• The TASP Web site (http://www.achancetoparent.org) for information about membership, conferences, and ways to connect with others on this area of interest.
• The International Association for the Scientific Study of Intellectual Disabilities, Special Interest Research Group on Parenting with Intellectual Disabilities (see http://iassid.org, under SIRGs select “Parenting”).
• The Healthy Start (Australia) Web site (http://www.healthystart.net.au) to see their national strategy for serving children of parents with learning difficulties.
• Publications by three of the leading researchers on the topic of parents with intellectual disabilities: Dr. Alexander Tymchuk, Dr. David McConnell, and Dr. Maurice Feldman.
• The Web site of Through the Looking Glass (http://www.lookingglass.org), one of the first agencies in the U.S. to serve parents with disabilities.

There are many opportunities for top-down (social policy) and for bottom-up (grass-roots/community) action and conversation to enhance the lives of families when a parent has intellectual disabilities. I encourage you to explore the field, and keep the action and conversations moving forward.

References


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Male youth, myself included at the time, are often not mature enough to handle the topic and will convince themselves that they know about it already rather than have an honest conversation with an adult.

the first time I actually felt labeled “different” was when I was in about fourth grade. I remember leaving my elementary classroom (my school day was not all mainstream classes yet – in the afternoons I was attending some special ed classes) and one of my friends went up to the teacher and asked, “Why can’t Nick stay in our class all day?” Now, I don’t know if the teacher thought that I couldn’t hear her, but I remember her saying, “Oh, don’t worry about it, he’s just different.” Now I couldn’t have been more than 10, but I knew what “different” meant. I remember going home and asking my dad if I was different. He simply said, “You are a lot different than she is.”

Likewise, when I was in junior high I worked up the courage all year to ask a girl at my bus stop out for ice cream. When she agreed to meet with me and we found ourselves eating ice cream and not talking much, she broke the silence by saying, “Nick, I don’t think we can see each other again. Isn’t there someone else like you that you would be interested in dating?” I don’t think that it initially occurred to me that when she said “like you” she meant “with a disability.” Interestingly enough, the answer to her question was no. There weren’t any other students with disabilities that I was interested in dating. The only other person who had a disability at my school was my good friend Josh; he and I had been great friends since preschool, but I knew I wasn’t interested in dating him! As I dug a little bit further in talking with her I found out that she had numerous other concerns about my disability; most of all she was concerned that I would pass my disability on to children that we would have. Keep in mind that I’m still sitting there with my ice cream in hand. Until this experience I had never thought how my disability would affect others in my life.

In situations like these I was able to have real conversations about my life with my dad. It was through these conversations where I learned that it was my responsibility to be knowledgeable about myself and explain my situation to other people.

When it came to my identity, disability, and sexuality I found that I was the driving force behind a lot of conversations that we would have. My dad was always available to talk to, and there wasn’t a conversation that was out of bounds. There were conversations that were challenging, and talking about sex was definitely one of those; but those challenges were not unlike any other father-son talk on the topic.

It is hard for men in our society to talk about sex. It may be part of our culture. And male youth, myself included at the time, are often not mature enough to handle the topic and will convince themselves that they know about it already rather than have an honest conversation with an adult.

When the book Where Did I Come From? (a book about reproduction) appeared when I was 13 years old, there was no way that I was ready for the conversation my dad tried to start about it. I remember it being very difficult for me to take the book seriously because of the subject and the cartoon format. I was not mature enough to handle the topic. But, I did take a look at it when I was on my own; that allowed me to take in the information, and then I approached him with questions on my own terms. In my experience, I gathered a lot of information about sex from school, friends and the world around me and then I would bring up questions with my dad. I believe this helped break things down for me and I did not feel like I was having a big conversation. Instead, I asked questions here and there and pieced things together. This made the nature of the discussion less anxious and more spontaneous.

There have been and there will always be assumptions about my abilities, about the things that I can do. But the only ones that I have to believe are those that I tell myself in the mirror. Today, I have a girlfriend, Jackie, and we have been together for almost three years. She’s wonderful. To my knowledge she doesn’t have any diagnosed disabilities, and she does enjoy ice cream!

I owe a lot of thanks to my dad for helping me become that confident guy in the mirror. Not a week goes by that I don’t talk to him about my life. We are very fortunate to have the relationship that we do; I love him for it. Talk soon, Dad!

David’s Perspective

I do not remember talking specifically about sex with Nick – I’m old now, however. I do remember that if he asked a question I would answer the question, or if I didn’t know the answer I promised to find the answer, and did. I believed answering his questions as they came up
was easier for him to digest than to have some big discussion where only ten percent would sink in, kind of like taking too much vitamin C – your body can only handle so much and the rest goes off as waste.

I do remember believing strongly he wasn’t any different than anyone else where sex was concerned, or in any other life experience for that matter. Sure, he may have to approach things a bit differently, but I/we focused on building self-confidence and concentrating on the things he could do really well, and less on things he had trouble with. I fully expected him to have girlfriends and date like most other adolescent males. It never occurred to me that he wouldn’t.

It was obvious early on that he wasn’t going to be a sports hero, so we did other things like camping and canoeing to give him different experiences he could enjoy, build confidence in, and become good at. He got really good at playing Nintendo, and was very confident he could hold his own with the neighborhood kids.

I also knew that the world wasn’t going to change for Nick, so we needed to find ways for him to fit in and build confidence. In my professional life I had seen too many families giving their kids with disabilities what I considered to be too much support. I was worried if I did that with Nick it would hinder his ability to become independent. I was actually accused of being mean to him when he was young because in the eyes of some I didn’t cater to him enough.

Nick has a great personality and that is very attractive to everyone: girls, boys, men and women. So armed with a great personality, confidence in himself, and good looks, I believed he had the tools to eventually go on to have strong relationships with the opposite sex and others of all ages. And he has.

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- 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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**Sexual Behaviors**

The last issue I want to address is regarding modern technology and sexual needs. Some of the people we support try to meet their sexual needs through the Internet and/or 900 numbers. We are very concerned that they might be exploited or abused due to their cognitive limitations and possible emotional vulnerabilities. Our policy states that we “Ensure that the treatment team is aware of consumer’s use of technology (such as accessing personal ads, calling sexually explicit 900 numbers etc.) in fulfilling sexual expression.” Also that we “limit the use of the Internet and/or monitor telephone calls if there is probable cause that the person is engaging in illegal activity.” Because the chat lines also have per-minute calling charges, we also try to keep a close eye on the expenditures of those who use them and catch any financial problem as early as possible.

**Conclusion**

In summary, I hope that service providers and family members understand the importance of supporting people with ID/DD regarding their sexual needs and desires. Unfortunately, far too many agencies are not willing to provide support, and rather try to repress a basic human need. If we are truly person-centered, then sexual needs, which are an integral part of the human personality, should be reflected in service plans and in a coherent, positive agency policy.

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**References**


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In This Issue...

- Self-Advocates Speak Up About Sex
- Sexuality Meets Intellectual Disability: What Every Parent Should Know
- Destination – Adulthood: Preparing Your Child for Puberty and Adolescence
- Parents Talk About Sexuality and Disability: Highlights of PACER Cross-Cultural Focus Groups
- Sexual Expression for Adults with Disabilities: The Role of Guardianship
- A Sexuality Policy That Truly Supports People with Disabilities
- Sex, Disability and the DSP: Ethically Supporting Sexual Choices
- People with Disabilities and Federal Marriage Penalties
- New Ways of Thinking About Parents with Intellectual Disabilities
- Personal stories, resources, and more

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