

oregon

PERSPECTIVES

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OREGON COUNCIL ON
DEVELOPMENTAL
DISABILITIES



Healthy Intimate Relationships

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**OREGON
COUNCIL ON
DEVELOPMENTAL
DISABILITIES**

The mission of the Oregon Council on Developmental Disabilities is to create change that improves the lives of Oregonians with developmental disabilities.

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From the Director

*I*n this issue of *Oregon Perspectives* we take up a topic that many would prefer to avoid altogether — dating, partnerships and marriage in the lives of people with developmental disabilities. Our intent is to show — through success stories — that healthy, intimate relationships are possible for people with developmental disabilities. We also want to acknowledge the struggles and risks along the way.

Many of us from the boomer and pre-boomer generations received little to no guidance at home or at school about sexuality and intimacy. That taboo may have lost some of its power for recent generations but not for many providers and parents of people with developmental disabilities. A common attitude seems to be that if we just ignore the fact that people with developmental disabilities are sexual beings with longings for intimacy and romance, then the issue will simply go away.

Obviously, that is not the case. The Council on Quality and Leadership conducted nationwide interviews with more than 6,400 people with developmental disabilities between 1993-2006. The results indicate that 72 percent of those interviewed said they have intimate relationships. We can choose to ignore the fact, but there it is.

There are good reasons why parents and providers might fear giving encouragement or support to adults with developmental disabilities who yearn for a special someone in their life. Love and sex come with certain risks, and relatives and providers are rightly concerned about anything that might increase exposure to abuse for family members or the people they support. But where is the line between concern for an individual's safety and respect for an individual's right to the pursuit of happiness? This is one of many questions we set out to explore in this issue of our magazine. And if we haven't succeeded in providing our readers with many answers, we hope we have at least stimulated some thinking and discussion.

I want to thank the individuals who agreed to share their stories in these pages. No relationship is perfect, and none of the people featured in these stories pretend that their relationships are trouble free. We appreciate their willingness to share details about their personal lives so that others can learn from their experiences.

Bill Lynch
Executive Director
Oregon Council on Developmental Disabilities



A Person-Centered Approach

By Keddie Burrows

*M*atters of intimacy, sexuality, and love are always complex topics to explore with another human being. Each one of these touches the most personal and vulnerable parts of a person's emotional core. All people, regardless of their intellectual or physical differences, have the desire for intimacy and love, and we develop our expressions of sexuality based on our developmental, environmental, and cultural experiences.

Supporting an individual with cognitive and/or physical disabilities in navigating these most complex needs requires a commitment of time and a willingness to hear the person without judgment. These are areas in a person's life that are easily misinterpreted and judged



Richard Jones and Ruth Morris (Council Vice-Chair)

what behavior puts them at risk for getting into trouble socially and with the legal system. The uninhibited manner in which some people with disabilities seek intimacy can be met with suspicion and even fear by those who don't understand.

People with disabilities may not be able to communicate their needs in a way that is easily understood, but they intrinsically know what it is they seek. The partnership between a support person who is committed to "listening"

“All people, regardless of their intellectual or physical differences, have the desire for intimacy and love.”

because of one's own values and experiences. It is important to first explore one's personal biases and feelings in order to be able to clearly "hear" the person being supported. "Listening" is not only about verbal communication - it can also include observing the person and researching the person's history, including his/her experiences and family's values.

All too often, people with disabilities have not been educated about the process of developing "healthy" relationships. This includes how to keep themselves as safe as possible in intimate relationships and understanding

and a person who wants to fulfill their most personal needs can often result in positive outcomes.

Keddie Burrows has 38 years of experience working with individuals and families. She is a Behavior Support Specialist with a private practice in the Bend area. She is also the Director of the Center for Studies of the Person, an international organization that provides training, personal growth opportunities, and promotes a person-centered approach in how to relate to others.

Respect, Honesty, and Loyalty — Gayle B. Gardner & Larry Betts, Portland

Gayle B. Gardner met her fiancé, Larry Betts, at a group home. Larry was moving out when I moved in, remembers Gayle. "Larry's roommate, Patrick, tried to get us together." They met in 1991. "I remember going to dances at Mount Scott Swim Center, where we danced and danced. We were girlfriend and boyfriend for a while before we got engaged."

"She is a very pretty girl," says Larry. "She is attractive. She is a very good person."

"I liked his honesty, most of the time," Gayle says with a smirk. "I like that he is loyal and honest. When I confide in him, he keeps it to himself. He is also a very hard worker."

"We respect each other," replies Larry.

In their relationship, they try to listen to each other. "Sometimes we don't agree and have to start over. We can apologize to each other after an argument." Gayle admits he can play devil's advocate. "Larry sometimes takes the other side when I go to him with a problem." They agree that they don't try to push each other but try to understand each other.

Larry adds, "We are good together. We are happy to see each other. When we got engaged, I told my Mama. My family was very good about it, happy. I like sharing time with Gayle and my family, six sisters and five brothers."

"It was my cousins who expressed concerns about the engagement," Gayle admits. When her family was opposed, she was very angry, even miserable about it. "I had a hard time pulling myself together. Larry was always there for me." They went to church together. "Larry



Larry Betts and Gayle B. Gardner

was always boosting my ego," she adds. "He was willing to get to know my cousins, which helped."

"Marriage is a big step," says Larry. "A big step."

So Gayle asks, "You still want me, don't you?"

"You know I do," states Larry.

Larry and Gayle agree they have to rely on honesty with each other and loyalty. "We would not be able to have another partner," starts Gayle. "We may have more stumbling blocks because we are different colors. We are different people, but we are dear to each other." She adds, "All people have problems with relationships, that wouldn't be just because we are people with developmental disabilities! People cannot read our minds! Sometimes I want to say, 'Go fly a kite!' to people. It is up to us what we do with our lives; it's not up to them."

Do they have advice for other people? "Be honest," Gayle says. "Respect each other's privacy."

"Be empathetic," adds Larry. "Keep things 'our business' when you need to."

Gayle B. Gardner represents Self-Advocates As Leaders on the national Self-Advocates Becoming Empowered (SABE) board. She is a long-time advocate who works

to educate others based on her own experiences. She is also a member of the Oregon Council on Developmental Disabilities.

Larry Betts has worked at Oregon Health Sciences University for 21 years. He competes in Special Olympics (especially basketball) and enjoys holidays with his family, including Gayle.

Both Gayle B. and Larry reside in Portland.

Training Modules on Healthy Relationships

- *Expect Respect* is a comprehensive prevention program designed to raise awareness of dating violence, teach skills for healthy relationship, develop youth leadership, and increase safety and respect on school campuses. *Expect Respect* can be implemented by advocates, counselors, and educators in middle and high schools, and youth serving organizations.
Expect Respect trainings are designed to:
 - Increase your capacity to start or enhance an existing dating violence prevention program,
 - Build community partnerships for prevention,
 - Learn strategies for ensuring a safe and gender-equitable learning environment for all students,
 - Implement *Expect Respect* including support groups, SafeTeens leadership training, and school-wide prevention strategies, and
 - Develop a culturally sensitive prevention program for your school and community.
- "Friends, Relationships, and More" power point training, by Susan Labhard, MSN, RN and Dean Westwood, MSW. These training materials cover friendships, relationships, family planning, sexual attraction, sex, and accommodations for persons with disabilities. E-mail westwood@ohsu.edu or slabhard@shrinenet.org
- Self-Advocates As Leaders has developed a 3-hour Violence Awareness training designed for groups of individuals with developmental disabilities. It includes information on how to recognize different types of abuse and how to protect yourself. 503-589-1664 or www.asksaal.org.
- Oregon Parent Training and Information Center is developing training on healthy relationships for families. It will be from a preventative position and will give ideas for IEP goals. It is important to start young and teach kids about their bodies and body parts of the opposite sex, social skills in relation to saying "no", puberty issue — what is private & public both body parts and places. 1-888-505-2673 or e-mail info@orpti.org.

Get more information at: www.austin-safespace.org/site/DocServer/Expect_Respect_brochure_2007.pdf?docID=3061

Dating and Boundaries

By Alice Massey, Eastern Oregon Regional Crisis Team Training

James knew he wanted to ask the girl across the room to dance, but he did not want to get in trouble for asking someone who was too young. He learned through the *Dating and Boundaries* classes that he could ask a staff person about her first. He then asked her to dance, they went on some dates, and he felt successful.

Several years ago, *Dating and Boundaries* classes were offered in eastern Oregon. The purpose was to give adults with developmental disabilities an opportunity to come together in a secure, private setting with peers and a facilitator to learn and work on social skills. The Eastern Oregon Regional Crisis Program, which sponsored the classes, wanted to be proactive about sharing concrete information about personal boundaries. The program began by training a group of facilitators to lead the trainings.



Facilitators of the training were neutral people (people not providing direct service to the group members). This made for a more free and safe environment for participants to share their thoughts and feelings. Each group set its own direction, aided by their facilitator.

Most participants had already received sex education in school, so their questions in this area had more to do with correcting misinformation they may have received since school. In setting the direction for their groups, most identified that they wanted assistance in

After participating in his support group, he engaged in the first consensual adult relationship with a woman that he had ever experienced.

Groups were formed for men and women separately; whenever possible, each group had a pair of facilitators — one male, one female. Having both a male and female facilitator made role-playing exercises more effective and enabled participants to voice their ideas and get feedback from both a man and a woman. It was a great model for respectful communication between men and women.

learning more basic social skills, such as how to ask someone to dance at a social event. At the end of the eight weekly classes, some groups decided to have a “graduation” event. The Pendleton men’s group met with the women’s group and held a dance where they practiced the skills they had learned. The men’s group voted to run another eight-week series of meetings, during which they wanted to learn

how to treat a woman on a date at a restaurant. This graduation included a dinner party with women they invited, where they used their newly-learned skills.

In looking back at the impact of the project, I think it was a worthwhile effort and worth continuing. We could have ensured better communication between support staff and the group. Issues that were going on elsewhere between participants were brought into group meetings, and if the facilitators had known what was going on ahead of time, they would have had a better chance to respond appropriately when problems came up in the group. Likewise, discussing difficult topics in meetings sometimes triggered emotional outbursts in participants later. It would have helped their support staff to be aware of these issues so they could be prepared to support the individual.

The greatest thing about the project was seeing the personal growth in a few of the individuals. One young man in particular, who was attending the Pendleton group, grew to trust his group facilitators and began seeking their help and advice in other areas of his life. He had experienced a lifetime of serious abuse and had, up to that point, perpetuated that cycle against others. However, after participating in his support group, he had higher self-esteem because he knew he had some additional people who were “on his side” and wanted to help him. After participating in his support group, he engaged in the first consensual adult relationship with a woman that he had ever experienced.

So, as with many things in the human services field, the satisfaction comes in seeing even one person have a better situation than they did before participating in the project.



Brian Gustafson and Reed Gibson are lifelong friends and share a loving relationship. Reed and Brian are each other's dates for dances, rodeos and outings with their friends. Their mothers, Michelle McKenzie (2nd from left) and Marty Erickson (far right), have been friends for 28 years. They met when Brian was two and Reed was six months old and have been friends ever since. "We help each other be better parents."

You Have to Do the Work

By Lindsay Stephens, La Grande

*T*he *Boundaries and Dating* training was absolutely useful! It was a place where people could talk, we could ask questions, and we could help each other out. I started as a participant but became a Facilitator because I liked what they were doing. People asked questions like, "How do I get someone to like me?" or "What can I do if I'm having trouble with my boyfriend (girlfriend)?" Now there is a Wallowa Lake trip every year, where we talk about dating and boundaries. I really like it.

When you are in a relationship, you first find a way to make friends. Then a friend might become a girlfriend or boyfriend. After you are in a girlfriend/boyfriend relationship for three months or a year, you never know where the relationship will go.

Relationships come and go all the time, especially girlfriend/boyfriend ones. Sometimes it is hard to be in a relationship. That's why they come and go. Sometimes you get in an argument. It can help to take a break and come back in an hour to solve the problem or work it out. If you need to, you can talk to someone to help you both work it out. Just because people come to me for advice does not mean that I can't get advice from others. I need it too. Advice is good, but you have to do the work.



Lindsay Stephens

Too often husband and wife relationships come and go too. It is okay not to get married. It's okay to be dating and not go that far. If you get married, you need to be ready to try to work through problems before breaking up or getting a divorce. You have to accept that some relationships end.

Lindsay Stephens is a Partners in Policymaking graduate who is active in La Grande. She believes that education and training are important for all of us to have healthier relationships.

In It for the Long Haul —

An Interview with Jerry Buchanan and Cindy Helvington

On our relationship:

Jerry: We met at Goodwill in 1975. We both worked there. We did not start dating right away, because I was married. We dated later.

Cindy: We have been together almost seventeen years. We have chosen to live together instead of getting married or going through a commitment ceremony (that costs money, too.)

Jerry: We don't want to make one of us lose benefits.

Cindy: Yes, why should someone lose benefits just because they want to be legally married? It doesn't make sense.

The biggest reason for our success:

Jerry: We each have our own friends. In our relationship we do not spend 24/7 together, so the other person has time to do his or her own things. Sometimes we even take separate vacations. Cindy goes to national conferences for work, but I like to go on some camping trips on my own.

Cindy: This is good, because on the days you have to do something on your own, you are not too dependent on someone else. I spend time with friends, and sometimes I spend the night in Salem so I don't have to commute all the time.

Things that are tough:

Cindy: When you marry, you marry the family. Some family members may not want to let go.



Cindy Helvington and Jerry Buchanan live together in Springfield, Oregon, with their cat, "Baby."

Jerry: In my first marriage, I didn't get along with my wife's family. When you marry someone, sometimes the in-laws want to run their kid's life. I wanted to marry the daughter, not the rest of the family. It didn't work out.

On jealousy:

Jerry: Other people can get jealous of our relationship because we've been together so long. Some people like to turn around and spread gossip. This just causes problems.

Cindy: I have been jealous, but I deal with it. I voice it to Jerry, and we talk through it. Jerry is on a bowling team with all girls. All the girls have a crush on him.

Jerry: Whatever, it doesn't matter to us.

Cindy: When the gossip circles get going, then one of our talks comes up. We learned to address it head on or it might turn into a big mess. This makes us stronger.

Jerry: It's different for all people.

Other good things:

Jerry: Sex is not the reason we have a long-term relationship; it is just a part of the whole thing.

Cindy: Jerry comes to me for advice on the computer because it's something I can do. This makes me feel good.

Jerry: We have the same likes and dislikes.

Cindy: You have to give 50/50. You have to give as well as take. This includes splitting up the housework.

Jerry: We work it out. Right now, I do housework, and Cindy brings the money home.

Cindy: I do the cooking. Jerry does a lot of the dishwashing, mostly because he doesn't like the way I do it!

Cindy Helvington is the Executive Director of Self Advocates As Leaders (SAAL.) She helped SAAL form in 1998. Cindy has been a leader in the self-advocacy movement for over 25 years. She is an active member of the local People First chapter in Eugene. In her spare time, you might find Cindy knitting or working on her laptop. Jerry Buchanan is involved in People First of Eugene and he goes camping with the group. He attends Lane Community College to study reading, writing, math, and how to use a computer.

Different Strokes

Devin Ackley and Kerri Fowler had a commitment ceremony nearly 13 years ago. They met when a mutual friend introduced them. "I had a crush on her right away," admitted Devin. "I guess she had one on me, too, but we didn't know that until we started dating later on."

Devin and Kerri are part of a large network of friends in the Eugene/Springfield area — a network that includes Jerry Buchanan and Cindy Helvington (See story on page 9). When asked for her opinion on what makes Cindy and Jerry's relationship work, Kerri started, "Well, she goes one way and he goes another. They go their separate ways." Devin added, "It works for them, going their own way. We are different that way. We like to spend more time together."

Devin and Kerri recently had some time apart when Devin traveled to Beijing to compete in the Special Olympics World Games. "He went to China for 17 days. He got a first and two second places," said Kerri, obviously proud of him. She admitted, "I missed him so much. We'd never been so long apart." She got by with help from her friends, especially lots of supportive phone calls. "I had a friend come stay with me, but it wasn't the same as having Devin here. She got on my nerves a little, but it helped."

"We each have our jobs we go to," said Kerri, "but it's nice to come home to each other." What works for Jerry and Cindy may not be the same for everyone; but, as Devin put it, "They've done it."

Devin Ackley and Kerri Fowler live in Eugene. Devin works at Dairy Mart and likes to stay active, especially riding his bicycle and going to movies. Kerri's favorite part of working at Goodwill is greeting people while in charge of the dressing rooms. Kerri enjoys coloring and going out with friends.



Benton County Classes Empower People

“From my experiences,” says Gloria Kim, Benton County DD Services Coordinator, “young and mature adults with developmental disabilities often wish to form an affectionate, close relationship but don’t know how to begin because of their lack of social skills and limited knowledge about relationships and sexuality. Despite these obstacles, they continue to hope someday they will meet the right person to marry and live happily together.”

Benton County DD Services has developed a three-tiered approach to teaching people about relationships. The first is a set of classes adapted from an excellent sexual health program called Male Advocates for Responsible Sexuality (MARS), which focuses on dating skills and sexuality. The second is a series of Life Skills classes, which covers many topics, including communication skills for couples. The third is a support group, known as Happy Trails, for people identified as sexual offenders.

The MARS-DD classes are designed to promote dating skills such as conversation skills training (including finding appropriate topics of conversation and maintaining communication), knowledge about human sexuality, sexually transmitted diseases, and use of contraceptives. The idea behind the classes is that people are more empowered when they understand how to appropriately express their sexuality and know how to set healthy boundaries. They learn responsibility in sexual relationships and the possible negative consequences of sexual activities.

For the Life Skills training sessions, Steve Yellan, a Qualified Mental Health Professional at Benton County DD services, has advice for those who conduct trainings for people



John and Cheryl Coonce, Redmond, on their 13th wedding anniversary.

with developmental disabilities. “Know your audience,” he says. “Don’t use too many words, and show excitement about your subject. Training is 2/3 entertaining and 1/3 delivering content. Use PowerPoint instead of printed material. People are visual learners, so do group involvement and role playing.”

Yellan has pulled together many materials on relationships, sexuality, communication and other topics for these training sessions. One popular relationships training he offers is called Coupling Up. “This was fun,” Yellan marveled. “It helped people understand what it means to be in a relationship and how to communicate when things get hard. People who have the least experience with relationships see them as the biggest mystery.”

The Happy Trails group provides support for people who have a history of sexual offense. Some of them come to the group mandated by a court order and others come because their ISP team or case manager asked them to come. Jasper Smith, Program Manager for Benton

County, adds, "Many people carrying the label of sex offender have poor impulse control. Weekly ongoing therapy and education, along with peer accountability, is effective for them."

According to Kim, "Research consistently indicates that there are higher incidents of sexual offense among people with developmental disabilities than in the general population, possibly because of their limited understanding, vulnerability, lack of knowledge on how to read social cues, fewer opportunities to express their sexual needs, and a higher rate of sexual abuse victims who then offend

others." Group members support and confront each other when they check in each week. The group helps each member see his or her sexual abuse cycle, and they write apology letters to their victims.

Smith claims that these training programs are beneficial. "People learn to show more appropriate behavior, learn more about how their bodies work and about safe sex. But mostly, people are learning to communicate with each other better.

Resources on Relationships and Sexuality

- The Sexual Health Network: www.sexualhealth.com
- Autism-Asperger's & Sexuality : Puberty and Beyond / by Jerry and Mary Newport ; foreword by Teresa Bolick. Arlington, Texas: Future Horizons, c2002.
- The Ultimate Guide to Sex and Disability: For all of us who live with disabilities, chronic pain and illness, by Miriam Kaufman, M.D., Cory Silverberg, and Fran Odette. Copyright 2003, Kleis Press, Inc., San Francisco, California.
- Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism, by Mary Wrobel. Published in 2003 by Future Horizons of Arlington, Texas.
- The Arc of United States policy statement on sexuality Adopted 2004. www.thearc.org
- The Attorney General's Sexual Assault Task Force began a statewide initiative in the summer of 2005 focusing on the prevention of sexual violence against people with developmental disabilities. The goals of the Initiative are:
 - To establish a positive image of and response to individuals with developmental disabilities as people with full human rights and needs, including healthy sexual relationships.
 - To develop a thriving support net that assists individuals in creating healthy relationships and lives, and comprehensive services that encompass all individuals and their specific needs.

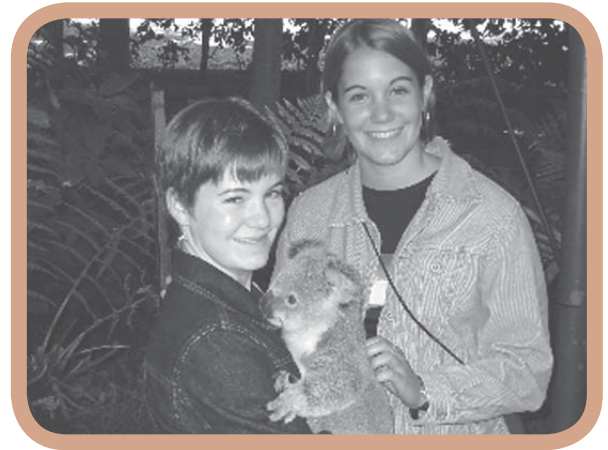
If you would like more information about the Task Force or its initiative, please contact Brie Akins at (541) 284-8275 or email briekins@oregonsatf.org

Reaching for Dreams

By Donna Rabin

I would like nothing better than to see my daughter in a supportive, intimate relationship with some one who loves her as we do. Getting to that is the difficult part, for all of us. We raised Anna to “be successful” in her life. Now she is trying to fulfill that success in a dream we hope is realistic for her.

People who meet Anna on the street may not know she has developmental disabilities. She is an attractive, petite young woman with strong social skills. In high school, Anna was able to be involved in a wide range of activities including marching band and sports. Teachers and coaches were willing to provide the supports she needed to be successful. Our small town, though limited in resources, has been positive because people know Anna and watch out for her.



Anna and her sister, Sarah

continued to talk about birth control, STDs, and making good decisions. Anna has a health care provider who is a wonderful source of information and support outside of our family circle. Although I do not go in with Anna when she has an appointment, I was able to speak with her provider early on to ensure that she understood how Anna communicates.

Anna is very involved in activities in our area that keep her socially connected. She takes

“We raised Anna to ‘be successful’ in her life. Now she is trying to fulfill that success in a dream we hope is realistic for her.”

We all expect teens who don’t have disabilities to make mistakes and learn from them. I expect the same for Anna, but because her judgment is not always good, the risks are higher when she does make mistakes. My husband and I worry about her vulnerability. We have tried to help her protect herself by beginning early discussions about sexually transmitted diseases (STDs), pregnancy, and safe sex

Anna is now 24 years old. She dates and for a while had a steady boyfriend. We have

karate, participates in a vocal jazz choir at the community college, and is part of an *a cappella* singing group. She works at Goodwill and also does volunteer work at two local businesses. Anna has a small group of friends who, like her, are striving to become independent adults.

We believe in the concept of self-determination, but we also struggle with the inherent dangers. We have always encouraged Anna to strive for her dreams. One of those dreams includes getting married and having children. We worry about Anna’s ability to take

care of a baby; she is still learning how to take care of herself. I would like Anna to be able to see a more complete picture and acknowledge how some of her limitations will affect choices she makes. We need to work this out!

The mental transition from caring for your child to supporting them as an adult is difficult for all parents. For the parents of someone who can be physically independent yet need significant supports, it is exceptionally hard to find the balance. Our greatest wish, and Anna's, is that she will find a partner who will respect and love her. We want her to be able to reach her dreams!



Anna and her mother, Donna

Donna Rabin is a pediatrician in Coos Bay whose first degree was in Special Education. When her younger daughter was diagnosed, Donna quickly looked for ways to modify programs that already existed in her small community, to best support Anna. In her work, Donna believes you need to start with the positive about a child, and then deal with the challenges.

Questions to ask about a sex education curriculum:

- 1. Does it teach about sexuality in context of relationships and consent?*
- 2. What values does the program promote? (There is no such thing as a sex education curriculum that doesn't teach values.)*
- 3. How will I know that my child learned the concepts taught?*
- 4. Does it teach the following: abuse prevention, disease protection, and avoiding unwanted pregnancy?*
- 5. Does it teach about sexual pleasure and ensure my child learns that his/her body is okay?*
- 6. Does it encourage my child to talk to me if he/she has questions or fears?*
- 7. What provisions does it make to teach to my child's learning capabilities?*
- 8. Does it teach general social skills? Does it teach about making friends and reciprocity?*
- 9. Does it teach about other ways of being intimate and showing affection besides sexual intercourse?*
- 10. Does it teach about the heart or just about the body?*

*From Sexuality: Your Sons and Daughters with Intellectual Disabilities, by Karin Melberg Schwier and Dave Hinsburger. Copyright 2000: Paul H. Brookes Publishing Co. Baltimore, Maryland, page 127.
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Ten Things to Keep in Mind

by John Agosta

1. Just like everyone else, people with developmental disabilities are sexual beings.
2. Not all people with or without developmental disabilities express themselves sexually. Some do. Some do not.
3. Sometimes simply having "someone special" in one's life is enough. Relationships may or may not be sexual in nature.
4. It is not all about being sexual with others. People with and without developmental disabilities sometimes seek to explore their own bodies.
5. When it comes to romance, people with and without developmental disabilities are capable of making good or poor choices.
6. It is too often assumed that people with developmental disabilities cannot parent well, due to their disability. Some have trouble parenting, even with support. Others make excellent parents.
7. The service system has ways of denying people with disabilities their sexuality. Many service providers unnecessarily impose rules on people to curb their sexuality or reduce opportunity for them to develop meaningful, even intimate, romantic relationships.
8. People with developmental disabilities are vulnerable to sexual abuse and too often fall victim to such abuse. Sometimes people do not report abuse because they are afraid that the privileges they have will be taken away "for their own safety."
9. People with developmental disabilities can be sexually abusive of themselves or others. Some may act inappropriately simply because they do not know how to act.
10. Parents, staff, and other disability advocates often feel awkward talking about sex and intimacy. So they often shy away from providing the mentoring and supports people with developmental disabilities need to grow into strong men and women capable of having healthy intimate relationships.



John M. Agosta, Ph. D.

John M. Agosta, Ph. D. is a Vice President at the Human Services Research Institute (www.hsri.org). He helped found *The Riot!*, a national e-newsletter for self-advocates (www.theriotrocks.org), and is involved with several projects to explore application issues related to self-directed supports.

The Riot! A National e-newsletter from the Self-Advocacy Leadership Network at Human Services Research Institute. Romance Issue, Volume 2, Issue 4, April 2006. <http://www.theriotrocks.org>

Healthy Relationships and Safe Sex: Tips for Self-Advocates, by Joe Meadours, copyright 2006. Personal viewpoint of a strong self-advocate who now lives in Alabama. For copies, contact Joe Meadours: c/o HSRI 7420 SW Bridgeport Road, Suite #210 Portland OR 97224 503-924-3783 x10 www.hsri.org

Love Beyond Labels

By Ann Blackburn

As soon as I met her it was an instant, deep connection, like our souls had been connected in another life. We had so much in common. We liked a lot of the same things and had the same philosophy on life. We started spending lots of intimate time together just hanging out and talking, about anything and everything. We could be together for hours, days without even noticing, time disappeared. I wanted to be with her all the time. I started to notice things that I hadn't noticed before, like a rainbow or a pretty cloud, and I would think of her.

It felt amazing and unbelievable that somebody was actually attracted to me physically. In my 30 years, I have had so little experience of having my body seen in a positive, not to mention a sexual and desirable way, I was feeling nobody could be attracted to my body. I needed to feel beautiful and desirable and feel somebody could be attracted to all of me. Having someone want me showed me I have something to offer, and I am just as desirable as the next woman. I longed to experience what it's like to have somebody take the time to explore and touch my body not because they had to but because they wanted to.

All my life I have had to have people, often people I just met, help me do my intimate and personal care and see things usually reserved for a lover. I need this very intimate help. Caregivers see my body; it is a job for them, and I'm used to it. It feels very matter of fact. Often people have an attitude and don't say a word to me the entire time that they are helping me. I have been able to form a pretty open and healthy attitude toward my body and sexuality



Ann Blackburn

in general. For me, it's more comfortable to not worry about prejudices and people's attitudes when I have my girlfriend stay over, especially in my own home.

There are still times when I can't help but think, "Who would want to date me — somebody with the degree of disability that I have? What do I have to offer?" Other times I wonder, "What's wrong with me? — I'm an amazing person with so many gifts to offer." As I continue learning about myself, I am realizing that it's in how I present myself: if I act self-conscious and withdrawn, people will see me that way; if I act bold and sure of myself, then hopefully I will get somewhere. People are fearful of something out of the norm; most people see an apparent disability and are unsure and run! I really think the severity of my cp (cerebral palsy) along with my speech is a big factor in why I can't get what I want most of all... someone special, to share my life with.

In my early twenties, I didn't know who I was and that included my disability as well as my sexuality. Even now I find it amusing to see people's reactions... a person with a pretty involved disability having sexual and romantic desires - throw in the fact that she is attracted to women, and I see puzzled looks and raised eyebrows. Here I am again, busting through stereotypical myths people have about disabilities.

It has been a long process trying to find an identity and a label that fit. No matter how many traditional labels society has, none of them really fit me 100 percent. A wise friend once said something profound, and I agree

wholeheartedly. "I am not lesbian; I am not bisexual; I am not straight; I am just sexual; I am me... attracted to people." I have adopted this philosophy for my own life. Now I realize by trying to fit into a societal box, my eyes have been closed to so many opportunities. It's the person inside whom I fall for, not the shell. I need an emotional connection, and I am slowly realizing that true intimacy is far more than sex.

Ann Blackburn has been a leader in the self-advocacy movement since 1997 and with Self Advocates As Leaders since 2000. Her passion is training about self-advocacy and advocating for people with disabilities. Beyond Portland, Ann also spends time in her native UK spreading the message of self-determination. This article is extracted from her memoirs.



"I'm an amazing person with so many gifts to offer," says Ann.

One Person at a Time

Based on a conversation with Joanne Fuhrman, Partnerships in Community Living

A customer came up to me and told me she and her boyfriend were interested in having sex. She asked if I could make sure it got on her ISP. It seems silly that a person would think they have to have ISP approval for every aspect of their lives. I told this woman that such a decision like whether or not to have sex is a decision she and her boyfriend needed to talk about. She could go to a team member for support, but she did not need approval for such a personal decision.

How a provider should support intimacy is like how a provider should support people: one person at a time. How we do things at Partnerships in Community Living, Inc. depends on the person and that person's support issues.

Some staff members can be young and inexperienced themselves, so they need to learn how to support a person respectfully. And some family members or guardians (not all) still want to deny that their family member has sexual feelings. Systemically, we all need to learn how to support a person to live their lives fully.

A bigger question is how to support people in dating and that whole process. Our agency does not have organizational policies on this, as it is really a person-by-person issue. Does staff stay around on a date? That depends on the person and the person's support needs. We do not have rules about boyfriends or girlfriends spending the night or being in a person's room.

“There really are no easy answers....”

The greatest barrier for supporting the sexuality of individuals with developmental disabilities is the system we have. We need to teach our system of people, staff, and families to be respectful and to respect privacy. For example, the full ISP meeting is not the place where a person wants to talk openly about a sexual item on the agenda (nor does it feel safe). In this case, a pre-meeting is more appropriate. Everyone on the team does not need to know about this person's intimate details, just those individuals the person trusts with that portion of his or her life. We are talking about issues of birth control, training, and masturbation. Would you want those things made public to everyone around you?

Instead, we talk about how you address this when you live with other people. For example, does the person need to have permission of roommates? What if this activity is a moral issue for a housemate? These are the kind of discussions you need to have when people share housing. It is much easier when someone lives alone.

It may also mean supporting a person to make informed choices, even choices as big as whether or not to get married. We have been in the position of sitting down and talking with an individual about the pros and the cons of marrying someone. For instance, people with disabilities need to know in advance that their

vouchers, SSI and medical card eligibility might be affected if they marry. It felt a little parental, but our responsibility is to support this person in making a decision.

And what if staff see one party or the other in a relationship as being a victim, rather than an equal partner? There really are no easy answers

to questions like this. Providers have to be willing to take on tough issues and help people work through them.

Joanne Fuhrman is the Associate Director at Partnerships in Community Living, Inc., a non-profit agency in Monmouth that provides residential and employment supports to people with developmental disabilities. She is also a member of the Oregon Council on Developmental Disabilities.



Sherri Osburn and Larry Sharp, of Portland

Working for a Great Marriage— Steve and Sally Kramer, Portland

“Over my dead body!” was what Steve Kramer’s dad said when he talked to him about marrying Sally. “Dad thought we wouldn’t be able to handle it,” says Steve. “But my aunt was supportive and helped me talk with him.”

“My mom wanted me to marry one day so I would not be alone. It was a dream she had,” reflects Sally Kramer. “But when we announced our engagement, it was emotional for my family. I was the little one. They were protective of me, especially my brother. We had to ask our families, in a nice way, to back off a little. Doing this really helped bring us together as a couple.”

The Kramers, married for 13 years now, agree that overall it has been wonderful, although it has been hard at times. Sally shares, “I found someone I can get along with.” Steve puts it clearly when he says, “Her strong points meet my weak points, and my strong points meet her weak points. This makes a stronger marriage.”

“We work to keep our minds in order and to



Steve and Sally Kramer

they cause stress. That’s where most of our arguments are coming from.”

Counseling has been important to the Kramers, as a way to work through difficult times. “If we have problems, we go to counseling. There, we learn from the problems that come up. It helps us to work it out,” says Sally. She advises others, “Before marriage, people need to realize that if you want to stay married, it will take work.”

“It might help to agree ahead of time that you will do counseling together sometimes. One person might resist, but it’s important.”

remember that we want to keep working for a great marriage,” says Sally. “Sometimes he doesn’t want to clean to the level I like, or he may not always want to listen to my opinion.”

“We battle over something silly like chores,” Steve adds. “Money disagreements are big;

It might help to agree ahead of time that you will do counseling together sometimes. One person might resist, but it’s important.” The Kramers receive support through Westside Semi-Independent Living. Steve reports, “If we need counseling, we can get it in our support plan.”

"A lot of people think people with disabilities can't get married and have kids. That is not true for all people with disabilities," Sally says. "But we know ourselves. We do not want to have kids. Some couples argue more because of the stress of raising a child. We need to focus on supporting ourselves."

The Kramers have final words of advice for everyone: "Don't interfere with a friend's marriage, but if you care about them, you can

be a part of their safety net when times are hard." Steve smiles, "My sister-in-law didn't think we would last six months. Here we are 13 years later, still married."

Sally Kramer currently serves on the Editorial Board of the People First Connection, a publication of Self-Advocates As Leaders. She has also held the office of Treasurer for People First of Oregon. Steve and Sally are both graduates of Partners In Policymaking. Steve enjoys time with Sally and working in his new job.

One Brother's View

By Russ Kramer

When Steve started talking about getting married, I tried to talk him out of it. I didn't think he could fully grasp what it entailed. If marriage doesn't work out for so many people without disabilities, what would their probability of success be?

I tried to wait and listen through Steve's bluster – he is a strong reactor when disagreed with. I waited and listened. Steve can be hard-headed and contrary, but he is a very capable person in many ways.

I didn't really know Sally very well, but once I saw Steve and Sally together, I felt better. They each have strong points and seem to complement each other well. Steve was making it with support from Westside, Inc., but I asked him, "If you can't take care of yourself, how will you take care of each other well?" I know he is not the best housekeeper.

My concerns were probably not unlike our other brother's, but Steve takes it better when I disagree with him. It is in how I talk with him. I live far away, and I know I can't make him do something, so I talk through consequences: "If you do this, this is what will happen. If you don't do this, this could happen." My role with

Steve has been to be a voice when asked, a person to bounce ideas off of. It works for us, because I am more like our mom in personality. Our other brother is more like our father. Steve doesn't always like my responses, but he listens to them.



Russ, Steve and Sally Kramer

The relationship between families has not always been great. Sally's brother is more of a motivator. He's one of the best advocates going. I'm more of a consequences guy. We each have been busy with our careers or raising our families, and Steve and I don't live in the same state.

Over the years, we all have learned a lot. I am glad Steve has found a job again. In our family, part of a man's identity is his work. Sally has lots of motivation and is consistent, making her more successful in getting and keeping work. This morning she walked four miles on the treadmill. Sally is a motivator to Steve in many ways. That's important for a couple. It is not all wine and roses, and we all have our warts, but bottom line is, they make it work.

Russ Kramer is one of Steve Kramer's brothers. They don't get to see each other often but they talk on the phone. He is a retired pilot who lives in Fresno, California.

Brotherly Love

By Mary Anne Seaton

Editors Note: Oregon Perspectives thought it was important to include an article about someone who, because of significant communication and other challenges, may never experience a romantic relationship. This view into Burleigh Seaton's relationships provides another perspective on intimacy.

Burleigh radiates. His face and eyes light up as if he's saying, "Here she is, she's home. I can get anything I want."

I am his connector, his interpreter.

Burleigh, who is now 33 years old, likes to be around people who like him and who joke and tease. When he was a young child, he did not. His world was so confusing that just being around people caused him a lot of anxiety. Burleigh needs to have people in his life who can relate to him and provide him with predictability. The people who are around him need to understand his different abilities and his challenges to communicate with people using limited language. For Burleigh, it's all about the person and how they value and treat him.

Other than that maternal thing between a mother and her child, Burleigh's relationships did not begin until after we had figured out how important it was to give him visual structure to make his world more predictable. Once we figured this out, his world began to make sense, and he could focus on other things.

The key people in Burleigh's life are his family — his father and I, and two brothers, Graham and Paterson. When Burleigh sees his brothers, he gets a big smile on his face and a big laugh comes with it. He smells our hair, adjusts our clothes, and picks lint off of us — making sure



Graham, Burleigh and Paterson Seaton

we are all neat and tidy. In return, his brothers will laugh with him and attempt to adjust his clothes, which doesn't always work.

It is difficult to describe the intimacy of the relationship we have with Burleigh. We read his eyes, the expression on his face, as he does ours. He follows elaborate routines without missing a beat. In the morning, he and his dad make coffee together. He opens the drawer for his dad to get the spoon out, opens the refrigerator and gets the beans out, adjusts the hot water on the stove, and puts the beans away. It is like he is an extension of his dad.

Burleigh sees the world so differently from the way we do, and he works hard to figure out how to live with us. He is a kind and wonderful person on good days and can make your heart melt. On bad days, when life is not so good for him, we are thankful that we have a bond with Burleigh, as life gets pretty stressful for all of us.

Over the years, there have been two additional people who have helped to make Burleigh's life really good. They began by understanding what was important to him and for him and how his autism affected all aspects of

his life. They provided him with the visual predictability that enabled him to become more independent. They each connected with Burleigh in much the same way that his family did — a relationship of trust that can only come from intimacy. They are his friends. They don't see Burleigh much now because their lives are very busy. It was incredible to watch what happened recently, when John came to see Burleigh. Burleigh made eye contact with John and sat with him, held his hand, and would not let him out of his sight. Both were smiling.

I have had the same expectations for all of my children: happiness and a good life. I don't look at Burleigh and think, "Oh my God,

he has autism." We accept who he is, and he accepts us with all of our flaws. As he gets older I sometimes think that if he hadn't had autism, his life would be similar to Graham and Paterson's lives. But it is only in passing. Burleigh, for the most part, seems happy. His life is filled with his choices and what is important to him and for him, and he has a bond with the most important people in his life — his family and closest friends.

Mary Anne Seaton is the mother of three sons who grew up in McMinnville. She says they are all beautiful human beings. Burleigh, the oldest, has taught many people about autism. Mary Anne has worked in the field of developmental disabilities for more than 30 years. She is an advocate for all people to have choice and control in their lives.

News and Views from the Oregon Council on Developmental Disabilities



Joe Carroll, Council Chair and his wife Linda, in San Diego

National Association of Councils on Developmental Disabilities (NACDD)

Joe and Linda Carroll attended the NACDD fall conference and annual meeting in San Diego. Joe is the Chair of the Oregon Council and Linda manages a regional Lifespan Respite Program. The purpose of the conference was to explore how disability advocates can work together to tackle common challenges and move as one toward a shared vision of the future.

Train the Trainer— Help Wanted Getting a Job

The Council recently sponsored person-centered employment trainings in three Oregon communities. Family members, youth with developmental disabilities and representatives from community agencies participated in the trainings. In November, the Council hosted a “train the trainer” event in Salem to build capacity to conduct more person-centered employment trainings across the state. All trainings were led by Tara Asai and Debra McLean from Asai & Associates and funded by the Competitive Employment Project of Oregon Vocational Rehabilitation Services.



A Train the trainer event on person-centered employment was held in Salem.

Celebrating our Community...and Taking Action



Defending the ADA

The **Road to Freedom** tour rolled into Salem last May to gather support for the Americans with Disabilities Act, which has been weakened in recent years by court decisions. The national



tour of ADA experts made three stops in Oregon on its sweep of the western states. Advocates were greeted by Secretary of State Bill Bradbury, participated in a public forum, and met with their legislators. Since the tour, the ADA Restoration Act has been introduced into Congress. The bill is designed to restore protections that have been stripped from the ADA, which were designed to protect the civil rights of people with

disabilities. The event was hosted by the Oregon Cross Disability Coalition and the Council.

Public Forum on Abuse

In December, 65 people gathered at a public forum in Salem to address concerns raised by *The Oregonian* regarding abuse of people with developmental disabilities in state-funded services. A panel of representatives from the Department of Human Services was on hand to provide information, answer questions and gather input on how to improve the health and safety of individuals in Oregon's system of community services. The forum was hosted by the DD Coalition and the Council.



James Toews, DHS Assistant Director, Seniors and People with Disabilities, addresses forum participants.



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To receive this magazine in the mail, join the Oregon Network! The Oregon Network is a collaborative statewide network of disability organizations and their members, including people with disabilities, their families, friends, providers, and policymakers.

Members of the Oregon Network share information with one another, receive Oregon Perspectives and other publications, can learn about training events and empowerment opportunities, and have the chance to voice opinions on policy issues at the local, state and national levels.

Visit www.oregonnetwork.org to join today.

Upon request, this publication can be furnished in an alternate format for individuals with disabilities by contacting the Council.



Richard Jones and Ruth Morris at their commitment ceremony.

Oregon Perspectives

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