

Relationships and Sexual Health for Adolescents and Adults with Intellectual and Developmental Disabilities



Karen Ward
Julie Atkinson



UAA Center for
Human Development
UNIVERSITY of ALASKA ANCHORAGE

AMAZING STORIES
BEING WRITTEN EVERY DAY.

WANTED:
GIRLFRIEND FOR

[REDACTED]
REQUIREMENTS: SWEET, SMART, PRETTY,
FUNNY, AND IN SHAPE GIRL.

AT LEAST A JUNIOR (SOME EXCEPTIONS).....

LOCATION: COME TO THE LIBRARY DURING A
LUNCH ON MON., TUES., THURS., AND FRI.

ON B LUNCH ON WED COME TO THE LIBRARY.

ASK FOR [REDACTED], I NEED A LOVING
RELATIONSHIP (I AM VERY LONELY, I'VE BEEN
LONELY MY WHOLE LIFE), AND I WOULD LIKE A GIRL
WHO WOULD CARE FOR ME, AND BE CARED FOR
BACK, I WOULD LIKE TO BE LOVED, I AM VERY
SMART, ARTISTIC, FUNNY, LOVES TO HAVE FUN,
ROMANTIC AND I AM SINCERE!!!

Reactions?

Fact or Fiction

People with disabilities are likely to have the same desire for sex and relationships as adults without disabilities.

FACT: A person with a disability (intellectual or otherwise), is likely to have the same desire for relationships and sex as other adults. However, because of their disability, people often experience barriers to forming, enjoying and engaging in healthy relationships...whether sexual or not.

Fact or Fiction

If people with disabilities, intellectual or physical, are protected and kept away from strangers, they will be less likely to be sexually abused.

FICTION: Most people with disabilities are abused by those who they know and trust. Abusers are often those who provide vital services to victims such as: residential care staff, drivers, personal care attendants, and even family or friends. The system that has been set up to provide for the needs of people with disabilities actually puts them at **GREATER** risk for sexual abuse.

Fact or Fiction

If people with disabilities receive sexual health education it will become hard for them to control their sexual urges.

FICTION: Many people think that if individuals with disabilities are given sexual health education they will become “over sexed” or start having “uncontrollable urges.” However, sexual health education, behavior supports and appropriate role-modeling promote healthy relationships, respectful and positive boundaries and safe sexual behavior.

Fact or Fiction

It is uncommon for people with intellectual disabilities to be arrested and charged with sexual offenses because of their disability.

FICTION: People with intellectual disabilities are frequently charged with sexual offenses because of inappropriate sexual behaviors such as public masturbation, assault and abuse of minors and now, cyber crimes. Many of these occurrences are a result of a lack of sexual education, role-modeling or oversight of on-line safety.

Common Assumptions

- People who experience IDD:
 - Are asexual
 - Have no desires
 - Have no awareness of possibilities
- Relationships lead to sexual intimacy
- Guardians have final say

Guardian vs. Individual Rights

Did you know that guardians CAN'T:

- Consent to an abortion, or sterilization
- Terminate the ward's parental rights
- Prohibit the ward from registering to vote or casting a ballot
- Prohibit the ward from applying for or obtaining a driver's license
- Prohibit the marriage or divorce of a ward.

What Self Advocates Have to Say

<https://www.youtube.com/watch?v=VL2NOTtD3C0&feature=youtu.be>

Sexual Rights

“People with [intellectual] and related developmental disabilities, like all people, have inherent sexual rights and basic human needs. These rights and needs must be affirmed, defended, and respected.

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of [intellectual] and related developmental disabilities, regardless of severity, does not, in itself, justify loss of rights related to sexuality.”

~Arc, Congress of Delegates (2004) and AAIDD Board of Directors (2004)

Value of Relationships

- There is strong connection between physical and mental health, and the quality of an individual's social network (i.e., friendships, relationships, etc.).
- Participation in social networks has been linked to lower rates of depression, stress, anxiety, and even death.
- People with a broad range of relationships develop a greater sense of identity, belonging, purpose, meaning, and self-worth.

Romantic Relationships are Important

- Partnered relationships are important in the lives of adults with developmental disabilities.
- Unfortunately, the time spent with girl/boyfriends is often limited, and they want to spend more time together.
- Relationships are very typical of people without disabilities from the context of how they describe a girl/boyfriend, how they spend time together and what they do together.

Barriers to Sexual Expression & Sexual Identity

- Lack of education
- Overprotection
- Social Isolation
- Societal attitudes
- Lack of clear policies



Violence and Problems in Relationships

- Violence against people with disabilities is a national problem.
- Other studies reported rates of victimization among people with disabilities ranging from four to ten times higher than peers without disabilities (e.g., Petersilia, 2001; Sobsey & Doe, 1991; Sobsey, Lucardie, & Mansell, 1995)

In an Alaskan study:

- 60% of those who reported having been in a relationship reported violence
 - 70% among women
 - 50% among men
- Types of abuse reported
 - Emotional (50%)
 - Physical (35%)
 - Sexual (15%)
- Almost 40% did not seek assistance from anyone
- Other studies show a high rate of interpersonal violence and victimization

Support

Supporting people to obtain stable, safe, and healthy relationships may mean many things:

- Fostering relationships that provide the emotional, social and physical intimacy people need for socio-sexual health.
- Providing individuals with the information and skills they need to protect themselves against abuse.
- Providing information about safe sex practices, different types of relationships and sexual orientations.

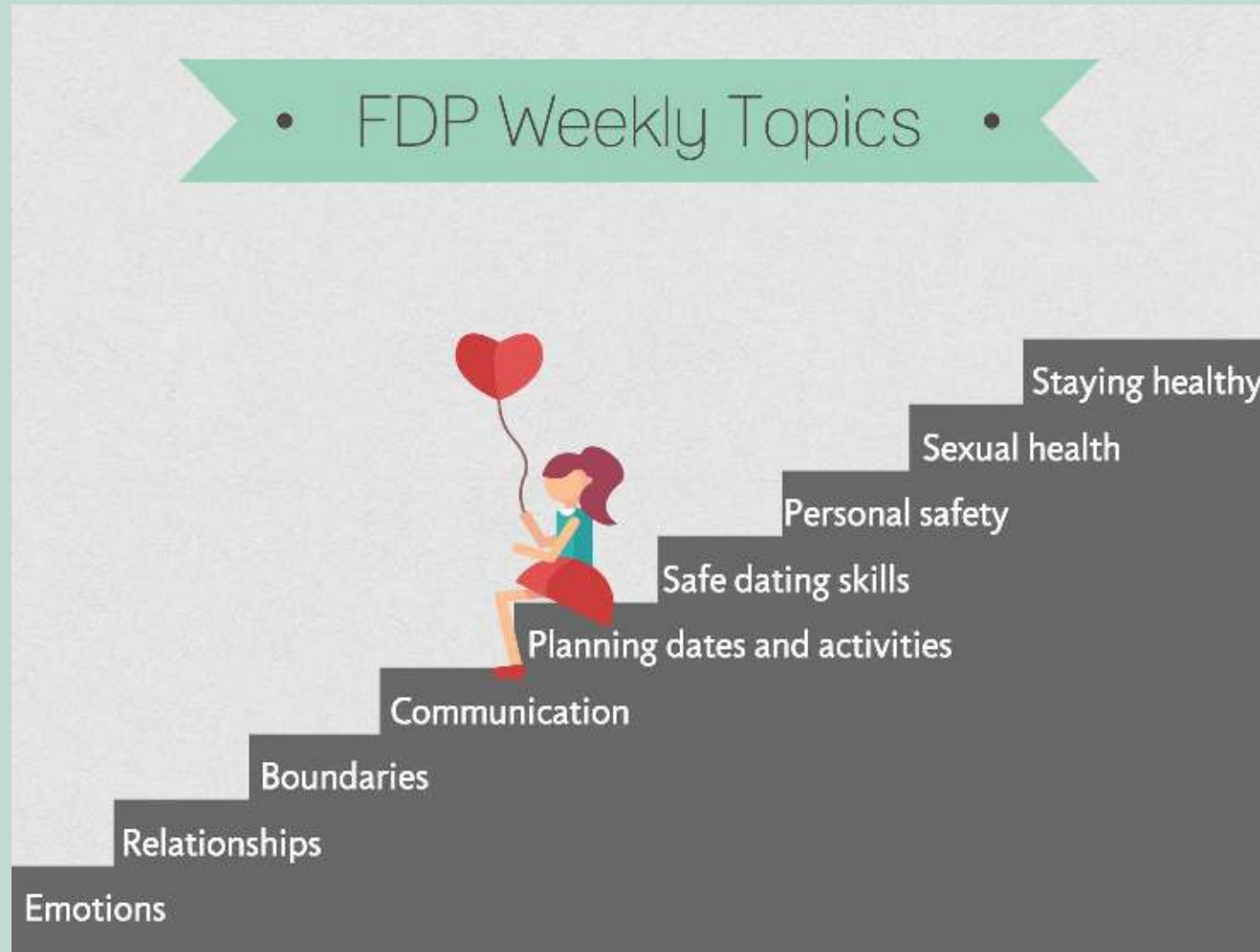
Support

- Providing and creating more, accessible, inclusive, and enjoyable opportunities for developing relationships, such as networking with peers outside of school or work hours.
- Assisting individuals in gaining more control over the parts of their lives that most affect interpersonal relationships.
- Providing safe environments so individuals can talk about their feels related to their sexuality.

Recommended Approaches to Teaching about Sexuality

- Focus equally on protecting oneself and on creating opportunities and helping people to acquire the skills necessary to experience sexuality in a positive way (Bruder & Kroese, 2005);
- Include information and instructions, modeling and rehearsing skills in role-play, and testing and rehearsing behaviors in situ (Bruder & Kroese, 2005; Egemo-Helm, Miltenberger, Knudson, Finstrom, Jostad, & Johnson (2007); and
- Collaboration between trainers, care providers, and individuals with disabilities (Blanchett & Wolfe, 2002).

Friendships and Dating – an example



Program Format

• Program Format •

- 20 sessions
- 1.5 hour sessions
- 10 weeks
-



one session of the week focuses on skill building using a group process



the other session of the week focuses on learning in place in a community setting

Program Delivery

- Program Delivery •

Train direct service personnel from local agencies as facilitators to deliver the program and build community capacity



16 hours of training



Orientation for caregivers



Co-ed groups of 6-8 participants

General Tips For Teaching Sexual Health

- Learning about sexual health and our bodies is a life-long process and doesn't end with one discussion.
- The earlier you start teaching someone about sexual health the easier the process is:
 - People are never too young to learn the correct names for body parts.
 - Teaching people about puberty before it happens may make it not so scary when it occurs.
- Is the material best taught in a group, or one-to-one?
- Use concrete language and avoid metaphors.

Teaching Moments

- Teaching moments happen every day
 - When watching TV or movies
 - While in the community
 - During personal care
 - When shopping
 - When interacting with others
- Pick your moment
 - Take a deep breath and relax...

Promoting a Full Life

- How do relationships (with or without) sexuality relate to a full life?
- As providers, how can we help to promote a full life?
- Acknowledging sexuality can help affirm status as a human being.
- Allowing and respecting the choice for sexual pleasure (alone or with others).
- As health care professionals, address sexual health issues and offer age appropriate preventative screenings (these are often missed for people with IDD).

Case Study Discussion

- Joan
- Jack

Resources

- The Health Bodies toolkits for Parents
 - One for girls with disabilities
 - One for boys with disabilities
- Download free
- <https://vkc.mc.Vanderbilt.edu/healthybodies/boys.html>
- <https://vkc.mc.Vanderbilt.edu/healthybodies/girls.html>

Questions?



Contact Information

- Karen Ward
karenw@alaskachd.org
- Julie Atkinson
julie@alaskachd.org
- Phone: 907-272-8270
- Website: www.alaskachd.org
- Facebook: www.facebook.com/alaskachd



UAA Center for
Human Development
UNIVERSITY of ALASKA ANCHORAGE

References

- Atkinson, J.P. & Ward, K.M. (2012). The development of an assessment of interpersonal violence for individuals with intellectual and developmental disabilities. *Sexuality and Disability*, 30 (3), 301-309.
- Blanchett, W. J., & Wolfe, P. S. (2002). A review of sexuality education curricula. *Research & Practice for Persons with Severe Disabilities*, 27(1), 43-57.
- Bruder, C., & Kroese, B. S. (2005). The efficacy of interventions designed to prevent and protect people with intellectual disabilities from sexual abuse: A review of the literature. *The Journal of Adult Protection*, 7(2), 13-27.
- Cambridge, P. & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability & Society*, 15(2), 293-311.
- Carlson, B. E. (1998). Domestic violence in adults with mental retardation: Reports from victims and key informants. *Mental Health Aspects of Developmental Disabilities*, 1(4), 102-112.
- Centers for Disease Control and Prevention. (2010). *Intimate partner violence: Risk and protective factors*. Retrieved from <http://cdc.gov/violenceprevention/>

References

- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8), 676-684.
- Copel, L. C. (2006). Partner abuse in physically disabled women: A proposed model for understanding intimate partner violence. *Perspectives in Psychiatric Care*, 42(2), 114-129.
- Egemo-Helm, K. R., Miltenberger, R. G., Knudson, P., Finstrom, N., Jostad, C., & Johnson, B. (2007). An evaluation of in situ training to teach sexual abuse prevention skills to women with mental retardation. *Behavioral Interventions*, 22, 99-119.
- Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accomodation in Northern England. *Journal of Applied Research in Intellectual Disabilities*, 17, 191-197.
- Gill, C. J. (1996). Dating and relationship Issues. *Sexuality and Disability* , 14 , 183–190.
- Nosek, M. A., Howland, C., Rintala, D. H., Young, M. E., & Chanpong, G. F. (2001). National study of women with physical disabilities: Final report. *Sexuality and Disability* , 19 (1), 5–39.

References

- Siebelink, E. M., de Jong, M. D. T., Taal, E., & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: Assessment of knowledge, experiences, and needs. *Mental Retardation*, 44(4), 283-294.
- Smith, D. (2008). Disability, gender and intimate partner violence: Relationships from the behavioral risk factor surveillance system. *Sexuality & Disability*, 26(1), 15-28.
- Ward, K.M., Atkinson, J.P., Smith, C.A., & Windsor, R. (2013). A friendships & dating program for adults with intellectual and developmental disabilities: A formative evaluation. *American Journal on Intellectual and Developmental Disabilities*, 51 (1), 22-32.
- Ward, K. M., Bosek, R. L., & Trimble, E. (2010). Romantic relationships and interpersonal violence among adults with developmental disabilities. *Intellectual & Developmental Disabilities*, 48(2), 89-98.
- Ward, K. M., Windsor, R., & Atkinson, J. P. (2012). A process evaluation of the friendships and dating program for adults with developmental disabilities: Measuring the fidelity of program delivery. *Research in Developmental Disabilities*, 33(1), 69-75.

Acknowledgement

Slides noted “Hamilton & Thorn” were adapted from “The Elephant in the Room” presentation originally developed by Joan Hamilton, RN & Barbara Thorn, RN for the 2013 Mental Health Trust – Grant Presentation and were used with permission.