

### PARENT WORKSHOP

FEBRUARY 10, 2021 7:30 PM - 8:30 PM

TALKING TO YOUR CHILD ABOUT

## SEXUALITY

INTRODUCTORY SEMINAR ON SEXUALITY AND DEVELOPMENTAL DISABILITIES

Presenter: Marsha Dorn, MS.Ed, BCBA
Program Analyst, Children and Youth
with Special Health Care Needs
Association of Maternal & Child Health Programs

PLEASE COMPLETE OUR PRE-WORKSHOP SURVEY: HTTPS://FORMS.GLE/VEEFWCLSEGMNHMIL8

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### During this workshop we will:

- Discuss misconceptions surrounding sexuality and the importance of comprehensive sexuality education
- Learn about human sexual development and developmental disabilities
- Gain knowledge about specific topics included in a comprehensive sexuality education curriculum
- Share tips and resources to help you and your child

Contact Brooke Levey with any questions: brooke@dsnmc.org

## **Sexual Health Resources for Professionals**

### Marsha Stepensky Dorn, MS.Ed, BCBA

- The Autism Spectrum, Sexuality and the Law Tony Atwood, Isabelle Henault and Nick Dubin
- Teaching Children with Down Syndrome about Their Bodies, Boundaries and Sexuality - Terri Cowenhouven
- 5 is Against the Law Kari Dunn Buron
- Unwritten Rules of Social Relationships Temple Grandin and Sean Barron
- Sexuality and Relationship Education for children and Adolescents with Autism Spectrum Disorders - by David Hartman
- Changing Inappropriate Behaviors by Dave Hingsburger
- I Said No! A Kid-to-Kid Guide to Keeping Private Parts Private by Zack King and Sue Rama
- Tom & Ellie series by Kate E. Reynolds
- What Makes a Baby by Cory Silverberg
- Sex is a Funny Word by Cory Silverberg
- The Hidden Curriculum for Understanding Unstated Rules in Social Situations for Adolescents and Young Adults - by Brend Smith Myles, PhD
- Queers on Wheels by Eva Sweeney
- Taking Care of Myself by Mary Wrobel
- Sexuality and Disability scholarly peer reviewed journal, subscription required

- Organization for Autism Research (OAR) Sex Ed for Self-Advocates https://researchautism.org/sex-ed-guide/
- National Council on Independent Living (NCIL) Sex Ed By and for People with I/DD: Videos and Guidebook https://ncil.org/sex-ed-for-individuals-with-i-dd/
- Vanderbilt Kennedy Center Healthy Bodies: A Parent's Guide on Puberty for Girls and Boys with Disabilities https://vkc.mc.vanderbilt.edu/healthybodies/
- Sexual Health Education for Young People with Disabilities —
  Research and Resources for Educators
  https://advocatesforyouth.org/resources/fact-sheets/sexual-health-education-foryoung-people-with-disabilities/
- Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed By: Kate Moss and Robbie Blaha http://conference.esc13.net/assets/beat\_the\_heat/docs/Blaha%20-%20Sex-Ed.pdf
  - 10 Myths about Sexuality https://www.youtube.com/watch?v=irt0mfIyCcA
  - Abused and Betrayed NPR Series
     https://www.npr.org/series/575502633/abusedand-betrayed
  - Amaze
     Animated videos for middle school and younger https://amaze.org/
- Amaze Jr. for Parents Playlist
  Designed to help parents engage young children (ages 4-9)
  https://amaze.org/jrparents/

# MEDIA

## Cup of tea: Consent https://www.youtube.com/watch?v=oQbei5JGiT8

- Cup of tea: Consent for Kids https://www.youtube.com/watch?v=h3nhM9UlJjc
- Homemade Love and Fingertips
   https://diverse-city.com/online-store-2/dvds/
- SexEd Mart
   https://sexedmart.com/product-category/special-needs-resources/
- The Ethics of Touch https://diverse-city.com/online-store-2/dvds/
- Urinal Etiquette
   https://www.youtube.com/watch?v=cr0ClHQC\_pY

## • *Special Bridge* https://www.specialbridge.com/

- My Special Match https://myspecialmatch.com/
- Autistic Dating https://autisticdating.net/
- Adult Autism Spectrum Friends, aka The Spectrum Friends, is for Autistic Adults (18 years and older) living in the D.C. area: Maryland, Northern Virginia, and Washington, D.C. Organized by an Autistic Adult, for Autistic Adults. We are an inclusive group, ALL Autistic diagnoses are welcome. Verbal or Non-speaking ALL Autistic adults are welcome to join.

http://www.meetup.com/adultautismspectrumfriends/

# DATINO

## The Ring of Safety: Teaching People with Disabilities to Be Their Own First-Line of Defense

Dave Hingsburger, Eastman, Quebec, Canada

This article states that people with disabilities need to learn skills to reduce their vulnerability to sexual victimization. Individuals with disabilities have often lived in protective systems that have assumed the responsibility for keeping people within those systems safe. When that protection fails the temptation is to blame the victim for the assault. This article presents six avenues of self protection: sex education; privacy awareness; the ability to non-comply; access to someone who listens; understanding of personal rights; and a healthy self-concept. Examples are given from clinical work.

"Her dress was short." This statement, if used by a rapist to explain why he dragged a woman into the bushes to rape her, would be seen as absurd (Piercy, 1976). In fact, it would be seen for what it was, an attempt to blame the victim. If the same statement was made at a party by friends of the victim, we would be horrified that those who professed to care for her would blame her for an act of violence perpetrated on her body. One of the major advances of the women's movement was to understand power and to place responsibility where it belongs (Shibley-Hyde, 1990). A consistent educational message has succeeded, for the most part, in eliminating or at least significantly reducing victim blaming (Gzowski, 1990).

Even though we have moved from blaming a woman for a rapist's behaviour, it is not uncommon to hear that someone was raped, molested or otherwise victimized because of her/his disability. Blaming a person's disability, lack of communication skills, or poor mobility for an assault on her/his body again excuses the rapist's behaviour. It is as if we would have to accept a rapist's answering the question, "Why did you rape Patty?" with a simple, "She was disabled." Clearly the idea that someone is raped because of her/his disability is as wrong-headed as thinking that a woman is raped because of her gender or a child molested because of her/his youth (Hingsburger, 1994; Everstine & Everstine, 1989).

Once the responsibility for the assault is placed back on the shoulders of the assaulter, the more important question needs to be asked, "What skills does a person need in order for her/him to reduce the risk of being assaulted?" Recognizing that there is an incredible percentage of abuse of people with disabilities is not the same as blaming the victim (Sobsey, 1994). This recognition should lead to an understanding that people with disabilities, maybe more than others, need to become their own first line of defense.

The Ring of Safety is a concept borne from clinical practice that suggests that people with disabilities need a set of skills that give them the ability to either repel unwanted advances or to report advances immediately upon occurrence (Hingsburger, 1994).

### Sex Education

People who argue against sex education for people with disabilities seldom understand the damage that is being done. While we may argue the benefits of sex education as it is related to sexual behaviour, there is no question that sex education is linguistic training (Monat-Haller, 1987).

Sex education acquaints people with the names for their body parts. This gives them the language with which to report abuse (Sgroi, 1989). For example, a young woman with a disability attempted to report abuse by saying she had a "stomach ache." This person had no language for her genitalia and the body part closest to her genitals which she could name was her stomach. She attempted to tell for over a year that she had been hurt. On first introduction to the word "vagina", she was able to clarify what she had meant and immediately reported clearly what had happened to her. Tragically, it was too late and the offender was long gone.

Too, sex education needs to teach that sexuality is a good and healthy part of all people (Hutchinson, 1990). Many people with disabilities have come to learn that sex is bad, sex is dirty and that sex will get you in trouble (Hingsburger, 1992). These sex-negative messages are dangerous (Money, 1979). First, they teach people that natural feelings are wrong (Forminchella, McIntyre, & Osterhourt, 1991). Second, they remove the concept of consent and pleasure from the issue of sexuality (Westheimer & Lieberman, 1988). This is dangerous in relation to abuse because people with disabilities, like all people, need to have "figure-ground" when it comes to sexuality. They need to know what is good and healthy so that they can discriminate what is wrong and bad. The sentiment that rape is not about sex, but about power, is learned only through being able to discriminate that sex is about consent and pleasure and that rape is about power and force. The difference is seen in comparison. Many people with disabilities who have had no sex education or poor sex education have failed to learn about love, warmth, caring and pleasure, and therefore cannot understand that which is good from that which is wrong.

### **Privacy Awareness**

Understanding privacy is difficult for people with disabilities. Not only is privacy an abstract concept; people with disabilities live in a world where "typical" privacy does not exist. Private rooms for typical people, like bathrooms and bedrooms, are routinely violated by staff who feel free to walk in on people with disabilities without knocking or without permission (McClennen, 1988). Staff may sit on a ledge in the bathroom and watch a naked person with a disability in the shower or the bath. They may sit and chat to a person with a disability who is sitting naked on the toilet.

More than this, people with disabilities routinely sit at meetings and have their menstrual periods, masturbatory habits, or other equally private issues discussed in front of ten or twelve other people (Hingsburger, 1990a). They learn that their life, their spaces and their bodies are open for public consumption. This is dangerous in that they do not have the basic concept of the privacy of their own bodies. When teaching about privacy people with disabilities begin to understand rules that exist for all people. In fact, it is in the teaching of privacy that many sex educators report that people with disabilities first report their victimization. It seems that learning that they own their bodies and that no one can touch their bodies without their permission gives them the concept with which to understand abuse. Privacy awareness is fundamental in abuse reporting. Sex education may give language with which to report abuse but privacy awareness gives the concept with which to understand it.

"No means no!" Or does it? Imagine for a second that it is chore night for Denis at the group home. The staff approaches and asks him if he wants to do the dishes and that Denis says, "No." What do you think should happen? If you believe that the staff should first pester and then force Denis to do the dishes then you also believe that "No doesn't mean no." This concept is difficult for staff and parents who require a smooth running routine to get everything that needs doing, done. The idea that a client has a right to refuse throws things out of kilter and into confusion (Flynn, Reaves, Whelan, & Speak, 1985).

Many argue that people with disabilities have to do certain things and that no one has complete choice or complete control in her/his life. This is a fact. All people are required to follow certain rules and complete certain tasks. There is no argument here. The problem is that staff and parents often don't discriminate linguistically between choice and demand. In the scene above the issue is not the chores, the issue is not the fact that Denis needs to pull his weight in the group home, the issue is not "testing", nor is it a power struggle. This issue is that the staff asked Denis if he wanted to do the dishes. Denis thought that this was a question and that therefore he had a choice. His choice was clearly, no. In teaching to non-comply the staff must learn to distinguish questions from demands. In this way the individual learns to assert her/himself in areas where there is a choice (Hingsburger, 1993).

Second to this is learning that there is an area which is always under our control and that is access to our bodies (Hyde, 1987). Third is learning that there is an area which is always a choice and that is if we want to touch another person's body (Will-Brandon, 1990). These concepts are of tremendous importance for people with disabilities to learn that they do not have to perform any sexual act that they do not want. This is a formidable first line of defense. Learning to say "No!" clearly to an abuser tells the abuser that this is a person who understands the rules. Anyone who understands the rules can report when the rules have been broken. This is not a person to be trifled with.

### **Someone Who Listens**

This is the only part of the *Ring of Safety* that does not involve a person with a disability directly. This aspect of the ring suggests that the person needs someone with whom s/he can talk. It is a tragedy that many people with disabilities have support staff around them all day but have no one to talk to when they need time to do so. Given that people with disabilities may have difficulty in communication or may take more time to communicate, one would think that staff and parents would have as their first priority listening when the person speaks. Yet, given all that is required in a day for parents and staff it is a regrettable circumstance that people with disabilities learn that their need to talk falls below their caregiver's need to do paperwork or other chores (Kirkham, Schilling, Norelius, & Schinke, 1986).

Listening to a person with a disability does not just mean hearing her/his words but it also involves seeing language (Light, Collier, & Parnes, 1985). Many people with disabilities, like all people, do most of their communication through non-verbal means. Tone, mood, affect and behaviour are only a few examples of how a person may report that s/he is or has been hurt. Those in direct contact with people with disabilities are the ones who will know the person and will be able to pick out subtle changes (Sovner & Hurley, 1983). As staff or others who support people with disabilities increase their ability to understand the behaviours, moods and gestures of individuals with handicaps they, by extenuation, increase the effectiveness of the communication attempts made by those in their care.

### **Understanding of Personal Rights**

All people with disabilities need training regarding their rights within the system in which they live (Turner, 1988). Systems have policies and procedures to protect people with disabilities from abusive staff and abusive caregiving, but often people with disabilities have no idea as to the boundaries set by the agency for the staff. It is important that agencies train people with disabilities in their rights and responsibilities within the agency. People to whom it is safe to report abuse need to be identified. Moreover, people with disabilities need routine scheduled access to this safe person so that they can discuss staff behaviour.

While this may seem idealistic, there are agencies who have set out this form of training and have used

advocacy agencies to come in and meet with their clients. This simple act communicates to all staff that the agency takes client rights very seriously. In fact, one agency reported that some prospective staff have not taken the job because they felt that "this approach upsets the natural relationship between a staff and client." The agency was jubilant in realizing that they had developed a process that would scare away employees who, while possibly not abusive, did not like the idea of clients having an opportunity to discuss staff's behavior.

### **Healthy Self-Concept and Self-Confidence**

In many self-protection training programs for women, a fundamental rule is taught regarding walking on the street after dark. That rule? Walk with PRIDE. It goes without saying that you can't walk with pride if you don't have it in the first place. One cannot "give" a person self- esteem (Hingsburger, 1990b). That comes through the person seeing that s/he is competent and loved. In fact, the two main self-statements involved in healthy self-esteem are "I am wanted" and "I am powerful" (Hingsburger, 1994). These two messages are learned through a person's interaction with the environment and with the people in it. While we cannot "give" self-esteem, we certainly can "take it away." As staff and parents are often in control of the environment, they can set up messages for the person to see her/himself as competent or they can set up messages for the person to see her/himself as stupid.

People who feel good about themselves, who feel wanted and powerful, are poor potential victims. These are people who can discriminate between abuse and love. These are people who can say "no" and who can report victimization. These are people who will stop abuse and abusers. This being the case, one would think that the major job of all people who support those with disabilities would be setting up environments wherein self-esteem is taught. Unfortunately people with disabilities often come to see themselves as a problem to be wished away.

"I wish you wouldn't bother me when I'm busy."

"I wish you would just sit down and be guiet."

"I wish I had had a normal child."

It takes a simple but fundamentally radical change in attitude to give different messages -- messages that communicate, "you are wanted" and "you are powerful."

### Summary

When working with people with disabilities one regularly meets people who are proud, strong and able self-advocates. This communicates that it is possible to be disabled, proud and strong all at the same time. Learning to see people with disabilities as being able to care for themselves, given the right training and the right messages, allows us to transfer the power and responsibility for self-protection to them. It is only when the people who are developmentally disabled can discriminate abuse, say no to it and report what happened that abuse will stop.

### References

Everstine, D. S., & Everstine, L. (1989). Sexual trauma in children and adolescents: Dynamics and treatment. New York: Brunner/Mazzel.

Flynn, M. C., Reeves, D., Whelan, E., & Speak, B. (1985). The development of a measure for determining the mentally handicapped adult's tolerance of rules and recognition of rights. *Journal of Practical Approaches to Developmental Handicap*, *9*, 18-24.

Forminchella, A., McIntyre, D., & Osterhourt, M. B. (1991). Tell it like it is: Straight talk about sex. New York: Avon Books.

Gzowski, P. (1990). Forward. In E. Dancia. Don't: A woman's word, (pp. ix-xiii). Toronto: McClelland and Stewart, Inc.

Hingsburger, D. (1990a). I contact: Sexuality and people with developmental disabilities. Mountville, PA: Vida Publishing.

Hingsburger, D. (1990b). i to I: Self-concept and people with developmental disabilities. Mountville, PA: Vida Publishing.

Hingsburger, D. (1992). Erotophobic behavior in people with developmental disabilities. *The Habilitative Mental Healthcare Newsletter, 11* (5), 31-34.

Hingsburger, D. (1993). I Openers: Parents ask questions about sexuality and their children with developmental disabilities. Vancouver: FSI Publishing.

Hingsburger, D. (1994). Just say know! Understanding and reducing the risk of sexual victimization of people with developmental disabilities. Eastman, PQ: Diverse City Press.

Hutchinson, M. (1990). The anatomy of sex and power: An investigation of mind-body politics. New York: William Morrow & Co.

Hyde, M. O. (1987). Sexual Abuse: Let's talk about it. Philadelphia: The Westminster Press.

Kirkham, M. A., Schilling, R. F., Norelius, K., & Schinke, S. P. (1986). Developing coping styles and social support networks: An intervention outcome study with mothers of handicapped children. *Child Care, Health and Development, 12* (5), 313-323.

Light, J., Collier, B., & Parnes, P. (1985). Communicative interaction between young nonspeaking physically disabled children and their primary caregivers. *Augmentative and Alternative Communication*, 1, 74-83.

McClennen, S. (1988). Sexuality and students with mental retardation. Teaching Exceptional Children, 20 (4), 59-61.

Monat-Haller, R. K. (1987). Speech-language pathologists as counselors and sexuality educators. Asha, 29 (12), 35-36.

Money, J. (1979). Interview. In P. Weintraub (Ed.), The Omni Interviews. New York: Ticknor and Fields.

Piercy, M. (1976). Living in the open. New York: Knopf.

Sgroi, S. M. (1989). Vulnerable populations, Volume 2: Sexual abuse treatment for children, adult survivors, offenders, and persons with mental retardation. New York: Lexington Books.

Shibley-Hyde, J. (1990). Understanding human sexuality. New York: McGraw-Hill.

Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities: The end of silent acceptance. Baltimore: Paul H. Brookes.

Sovner, R. & Hurley, A. (1983). The subjective experience of mentally retarded persons. *Psychiatric Aspects of Mental Retardation Newsletter*, 2 (11), 41-42.

Turner, T. S. (1988). Human rights concerns in health care institutions. Spokesman, February, 17-18.

Westheimer, R., & Lieberman, D. (1988). Sex and morality: Who is teaching our sex standards? Boston: Harcourt, Brace, & Jovanovich, Publishers.

Will-Brandon, C. (1990). Learning to say no: Establishing healthy boundaries. Deerfield Beach, FL: Health Communications.

More of Dave's published works can be found at Diverse City Press web site http://www.diverse-city.com