

Healthy Sexuality

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Goals of this session...

- ▶ Participants will:
 - ▶ Consider definitions of:
 - ▶ 'Healthy'; and
 - ▶ 'Sexuality'
 - ▶ Learn about the ways in which values and attitudes toward sexuality have effected services and supports for people ;with ID in the United States over the past 130+ years;
 - ▶ Consider aspects of 'healthy systems' in relation to sexuality and people with intellectual disability;
 - ▶ Learn about New Mexico's own path toward our current systems of supports related to sexuality and ID.

Foundations

1992 amendments to the Rehabilitation Act state that:

“Disability is a natural part of the human experience and in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society. [Sec. 2 (a) (3)(A-F)]

Foundations

“Individuals who have developmental disabilities have the same basic legal, civil, and human rights as other citizens. Sexuality and fertility concerns are natural experiences for persons who have disabilities. *However, violation of human rights is nowhere more evident for individuals who have developmental disabilities than in the area of sexuality*”

(Watson, Venema, Malloy, & Reich, 2002, p. 19, emphasis added).

Foundations

- ▶ “It is unethical for therapists to take away one behavior without replacing it with another” (Hingsburger & Tough, 2002, p. 8)
 - ▶ If your only goal is ‘eliminate’ or ‘reduce’ have you actually done anything?
- ▶ “Our energies are better put to eliminating the *need* for difficult behavior than in trying simplistically to eliminate the behavior itself” (Lovett, 1996, p. 94).

Foundations

- ▶ “People with developmental disabilities can develop healthy sexual relationships if they live in healthy systems” (Hingsburger & Tough, 2002, p. 8).
 - ▶ We are ‘the system’
 - ▶ Are we ‘healthy’?

Quick Exercise:

- ▶ Write down the most 'edgy', 'embarrassing', or 'fulfilling' sexual experience (real or imagined) that you have ever had. Take some time to think about it.
- ▶ Now - share it with the group of people around you and see what they think about your choices.

JUST KIDDING...NOT SERIOUSLY...OK - You
can stop now...TMI...

**BUT - CONSIDER THE FACT THAT WE ASK
MANY OF THE PEOPLE WE SUPPORT TO
DO JUST THAT - ALL THE TIME**

- ▶ What would this do to your own concepts of sex/privacy/'appropriate'?

In American historical context:

“The past is never dead...it's not even past” - William Faulkner

- ▶ “Because of the negative history experienced by people with disabilities, it is not possible to discuss any sexual behavior of persons with a disability without also discussing the environment in which they live or have lived “ (Hingsburger & Tough, 2002, p. 10).
- ▶ 1850-1900
 - ▶ Not a lot of focus on sexuality
 - ▶ Training schools
- ▶ 1900-1950
 - ▶ Eugenical sterilization
 - ▶ People with I/DD as ‘posing a risk’
 - ▶ The Menace of the Feebleminded - eliminate the problem

In American historical context...

- ▶ 1950-1970s
 - ▶ Institutionalization - out of sight, out of mind
 - ▶ People with I/DD as 'at risk'
 - ▶ Eliminate sexuality via segregation and aversive conditioning
- ▶ 1970s-1980s
 - ▶ An increasing focus on education and the role of environment
- ▶ 1980-1990
 - ▶ Rights based approach
 - ▶ Self Advocacy movement
 - ▶ Deinstitutionalization

In American historical context...

- ▶ 1990s-2000s
 - ▶ Moral panic and the second wave of 'the menace'
- ▶ 2010s →
 - ▶ The intersection of Rights and Risk;
 - ▶ We can see elements of all the previous eras:
 - ▶ Roadblocks to relationships;
 - ▶ What if...?
 - ▶ Emotional isolation;
 - ▶ Education yes, but little opportunity.

Consider this...

- ▶ Many conversations about people with ID having sexual opportunity/relationships revolve around the 'What ifs...'. The underlying implication of liability if something 'goes wrong'.
 - ▶ These are legitimate concerns but...
- ▶ We may be equally liable/negligent if we fail to provide for opportunity/access/relationships.
 - ▶ This could be seen as violation of basic human rights.
- ▶ More on the Dignity of Risk - Duty of Care this afternoon...

What do we mean when we say 'sexuality'?

- ▶ Where does sexuality begin?
 - ▶ “Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction” (World Health Organization, 1975)
 - ▶ “Sexuality is the essence of being [human]; it is the lens through which a person views the world. There are biological, medical, social, psychological, spiritual, cultural, and legal aspects to sexuality... [T]hese aspects differ depending on where, when, and how you live; who is raising you; and what is personally important to you” (Walker-Hirsch, 2007, p. 3)
- ▶ Where does it end?
- ▶ LOVING RELATIONSHIPS

What do we mean when we say 'sexuality'?

- ▶ HYGIENE
- ▶ ANATOMY/PHYSIOLOGY
- ▶ PERSONAL SAFETY
- ▶ FREINDSHIPS
- ▶ PREFERENCE/FANTASY
- ▶ LOVING RELATIONSHIPS

- ▶ AND YES, INTERCOURSE

What do we mean when we say 'healthy'?

- ▶ Is it *just* about preventing disease and pregnancy?
- ▶ What about pleasure?
- ▶ The 'privacy trap'
 - ▶ Policies may state that sexual activity is allowed 'in private areas' ...but
 - ▶ 'On the ground' practice often provides no *actual* privacy.
 - ▶ Leads to: misinterpretation, 'trouble', and 'leaky boundaries'

What do we mean when we say 'healthy'?

- ▶ Education
- ▶ Privacy
- ▶ Respect/Dignity
- ▶ The spectrum of sexuality
 - ▶ Opposite sex, same sex, asexual
 - ▶ Gender identity
- ▶ Consent
- ▶ Assent

How do we know when sexuality is not healthy?

- ▶ Healthy until proven otherwise
- ▶ Does 'healthy' mean "nothing goes wrong"?
- ▶ Cultural norms, mores, customs, laws, etc.
 - ▶ What is accepted, not accepted, pathologized, honored?

New Mexico's Unique Progression

- ▶ Beginning in 1995 New Mexico's Developmental Disabilities Division "established a plan to meet the sexuality needs of individuals who have been previously institutionalized and develop capability within the state to address individuals' sexuality needs" (PoA, 2006, p. 94).
 - ▶ (a) Individual Person Centered Sexuality Assessments;
 - ▶ (b) recommendations regarding interventions in situations of problematic sexual behavior;
 - ▶ (c) "provision of training and technical assistance to provider agencies;
 - ▶ (d) limited treatment to individuals; and
 - ▶ (e) technical assistance to generic service providers"

New Mexico's Unique Progression

- ▶ In 2006 the state was instructed to:
 - ▶ “develop and evaluate a tool specific to assessing sexuality deviance;...and increased training initiatives for teams and practitioners throughout the state” (p. 94).
 - ▶ Specifically, DDS was directed to adopt a Sexuality Services Plan that included a clearly outlined process for “assessing risk, evaluating needs, and planning, delivering, and monitoring supports to persons with sexually inappropriate or sexually offending behavior” (PoA, 2006, p. 98).
- ▶ In response to this NMDOH contracted with Jim Haaven.

New Mexico's Unique Progression

- ▶ Since 2006 we have:
 - ▶ **Developed the Preliminary Risk Screening service**
 - ▶ Over 200 teams have participated
 - ▶ **Aided in the development of the ARMIDILO-S**
 - ▶ Part of the 'new wave' of risk assessment theory and practice
 - ▶ **Firmly established the Friends and Relationship curriculum**
 - ▶ Many hundreds of participants from all parts of the service system
 - ▶ **Achieved 'Waiver service' status for both of these programs**
 - ▶ Unique in the United States
 - ▶ ***Introduction to Sexuality for People with I/DD***
 - ▶ Many hundreds of participants (CM, BSC, Serv. Coord., DDSD staff)

HEALTHY SYSTEMS

- *What we can control* -

“It would be cruel to work with people with disabilities to incorporate sexuality and eroticism into their sense of self and their expectations and [then] leave them in the very system that forced them to divorce themselves from their sexuality in the first place” (Hingsburger & Tough, 2002, p. 10).

HEALTHY SYSTEMS

- 4 Essential Components -

(Hingsburger & Tough, 2002)

▶ 1 - Clear Policy

- ▶ At agency and system levels

- ▶ “Good agency policies do not just spell out what is forbidden, but also what is allowed” (p. 10).

▶ 2 - Education

- ▶ Tailored for all stakeholders

- ▶ “Raising the subject can lead to shouts of denial and disapproval and threats of litigation. Not raising the subject though, simply continues the damage caused by denial” (p. 10).

HEALTHY SYSTEMS

- 4 Essential Components -

(Hingsburger & Tough, 2002)

▶ 3 - Encouragement of self-advocacy

▶ Negotiation vs. advocacy

▶ “‘Help to advocate’ does not mean ‘be the advocate for’” (p. 11).

▶ The difference between advocating *for* and advocating *with*...

▶ 4 - Relationship training

▶ “It is more than social skills training. It is teaching about personal safety...and loving relationships” (p. 12).

Where the rubber hits the road...

▶ AGENCY POLICY/TRAINING

- ▶ Addressing BOTH prevention of abuse AND self-determination? (Griffiths, Owen, Lindenbaum, & Arbus-Nevestuk, 2002)
- ▶ Ongoing?, Check-ins?, 'Fire Drills'?

▶ DIRECT SUPPORT PROFESSIONALS

- ▶ At the crossroads of risk and rights - daily (in addition to everything else...)
- ▶ What education and support do we provide? What education and support do *you* provide?

▶ 'RISKY' SITUATIONS/HISTORY

- ▶ Well sure...this is all fine and good for most people - but not for the individual I support - s/he's too...; s/he has...; s/he might...
- ▶ The power of the past v. present powers

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