Supporting the Whole Person: Sexuality and People with I/DD

CHEMRX

Residential Living Seminar

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Living an ordinary life is a challenge but living an ordinary sexual life, in the sense of exercising rights over your own sexuality, is to live a life of defiance. As yet, it is a life which services have done little to support.

An Ordinary Sexual Life? A Review of the Normalization Principle as it Applies to the Sexual Options of People with Learning Disabilities

Hillary Brown, *Disability and Society*, vol.9, 1994, p. 142

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Sexuality

All human beings have a need to care and be cared for. Ongoing communication and contact with others is essential to our physical and psychological health. Our sexuality plays an important role in that communication process. Sexuality is the way we define ourselves as men and as women. The definition is an important part of our self-esteem and can influence our interactions with others. The quality of our interpersonal relationships is, to a large extent, determined by how good we feel about ourselves as people worthy of receiving, and capable of giving, affection. Sexual activity is our most intimate way of expressing and receiving affection.

Choices: A Guide to Sex Counseling with Physically Disabled Adults by Neistadt and Freda, 1987
SIECUS Guidelines for Comprehensive Sexuality Education

These guidelines are based on specific values related to human sexuality and are consistent with values that reflect the beliefs of most communities in a pluralistic society. Each community will need to review these values to make certain the program is consistent with community norms and diversity. Some of the values inherent in the Guidelines include (partial listing):

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• Sexuality is a natural and healthy part of living.
  • All persons are sexual.
• Sexuality includes physical, ethical, social, spiritual, psychological, and emotional dimensions.
  • Every person has dignity and self-worth.
• Individuals express their sexuality in varied ways.
• Families share their values about sexuality with their children.
• In a pluralistic society, people should respect and accept the diversity of values and beliefs about sexuality that exist in a community.

• All children should be loved and cared for.

• All sexual decisions have effects or consequences.

• All persons have the right and the obligation to make responsible sexual choices.
• Sexual relationships should never be coercive or exploitative.

• Abstaining from sexual intercourse is the most effective method of preventing pregnancy and STDs/HIV.

• Premature involvement in sexual behaviors poses risks.
Yesterday’s
Questions, Concerns and Suggestions

• Are people with intellectual disabilities sexual? Are they even interested in sex or intimacy?
• The sexuality/sexual feelings/sexual activity of the individuals we support isn’t really any of our concern, is it?
• Do provider agencies have a responsibility to provide education or counseling about sexuality? We have a lot of other (more important/pressing…) things to think about (OPWDD, The Justice Center, CQL, staffing shortages, finances, ever changing rules and regulations).
• Aren’t parents the ultimate decision makers about their child’s sexuality/sexual expression and relationships?

• Shouldn’t we be protecting people from the possibility of bad/negative/hurtful things happening if they engage in sexual activity?

• Who am I to determine if a person can consent to sexual contact—no one assesses my ability to consent! It’s a part of life and everyone else is doing it!

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Today’s Focus

• Developing social and relationship skills
• Finding people to develop on-going, meaningful relationships with
• Consent in the era of CQL
• Continuing lack of accessible, appropriate sexuality education and counseling (childhood through adulthood)
• Gender and orientation
• Assessing, understanding and treating challenging sexual behaviors
• Developing and supporting opportunities for living together/marriage for those who desire

• The question of rights vs. responsibilities in the age of CQL and Personal Outcome Measures (POM)

• Social media, the Internet, iPods and cell phones

• Pornography (sometimes described as “sex ed”)

• Lack of productive discussion of sexuality and sexual rights in the self-advocacy movement

• The right to become a parent

• Creating a “sex positive” agency culture

• The changing influence of parents given CQL, POMs
How do we create a “sex positive” agency culture?

• Understand that sexual rights = human rights
• Leave no one out of the conversation: all people are sexual beings. Sexuality is expressed in many different ways.
• Develop ethical agency policies and procedures.
• Provide training to all staff, parents/guardians, boards
• Use positive, non-shaming language in writing, verbal interactions.
• Say the words! Don’t speak in code.
• Commit to provide active treatment including counseling, education and behavior support as well as opportunities for social skills development
The people we support need and want sexuality counseling, they need and want sexuality education, they need and want therapeutic support related to relationships, they need and want opportunities to take safe, educated risks to meet their goals and to have any chance of making their hopes and dreams come true.

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Psychosexual Assessment and Treatment Model

Clinical Issues/Service Continuum
Progressive Specialization of Services

Matich, Crocker and Boyle*

*with 2016 edits and additions by Pamela Boyle, MS
PSYCHOEDUCATION

Sexuality Education and Training

- Basic human awareness (myself and my world)
- Anatomy and physiology
- Self-identification (gender, attraction, orientation)
- Self-esteem, self-concept
- Abuse awareness and prevention
- STD awareness and prevention
- Understanding consent

Strategies

- Assessment of knowledge, attitudes, values
- Socio-sexual history
- Individualized sex education
- Sex education groups
- Picture-based learning
- Life Horizon materials
- Abuse awareness and prevention group
- Consent education and assessment

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**INTERPERSONAL**

**Skills Training in Interpersonal Relationships**

- Basic social and friendship skills
- Marriage and Committed Relationships
- Basic dating skills
- Understanding intimate relations
- Self-identification: gender, orientation, identity, attraction, expression
- Issue specific therapy including pregnancy and parenting issues

**Strategies**

- Facilitated socialization groups
- Intimacy education
- Couple counseling
- LGBTQ support
- Consent assessment
- Men’s support group
- Women’s support group
- Parent support/training

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TRAUMA

**Trauma Therapy**

- Acute victim issues
- Chronic trauma issues: PTSD
- Delayed trauma response issues

**Strategies**

- Taking a sexual history
- Trauma assessment: Trauma Symptom Inventory, Post Traumatic Stress Inventory
- Trauma and I/DD Flow Chart
- Individual Therapy
- Project Pride group (abuse recovery)
- Collateral Therapy
Sexual Aggression, Boundary Violation, Sexual Offender Behavior Assessment and Treatment

- Assessing risk for offending behaviors: “soft signs”
- First time offender assessments and treatment
- Repeated offense behavior assessment and treatment

Strategies

- Counterfeit Deviance assessment
- Other offender assessments
- Sexual compulsivity assessment
- Boundary disorder assessment
- Individual treatment
- “Project RESPECT” group tx
- Collateral therapy
- Medication assessment
- Staff/family training, support
I AM HUMAN AND I NEED TO BE LOVED
JUST LIKE EVERYBODY ELSE DOES.