Wisconsin Public Psychiatry Network Teleconference (WPPNT)

• This teleconference is brought to you by the Wisconsin Department of Health Services (DHS), Division of Care and Treatment Services, Bureau of Prevention Treatment and Recovery and the University of Wisconsin-Madison, Department of Psychiatry.

• Use of information contained in this presentation may require express authority from a third party.

• 2019, Reproduced with permission.
WPPNT Reminders

• Call 877-820-7831 before 11:00 a.m.
• Enter passcode 107633#, when prompted.
• Questions may be asked, if time allows.
• To ask a question, press *6 on your phone to un-mute yourself. *6 to remote.
• Ask questions for the presenter, about their presentation.

• The link to the evaluation for today’s presentation is on the WPPNT webpage, under today’s date:
Jessica Penwell Barnett, Ph.D.
Sociology & Anthropology
Wright State University
Dayton, Ohio

Alexandra Kriofske Mainella, Ph.D.
Counseling Education and Counseling Psychology
Marquette University
Milwaukee, WI

JoEl Demant, LSCW
joel.demant@gmail.com
Milwaukee, WI
“Education Is Not the Filling of a Pail”,
But the Encouragement of Ongoing Conversations.*

Yeats, Misquoted

*Which eventually leads to professional, program and organizational action.
Today’s Agenda

• Sexuality as a central aspect of being human throughout life.
• Sexuality as a human right.
• The development of sexual self concept and the impact of disability.
• Addressing each person’s sexuality as a core domain of service provision as the responsibility of services providers and organizations.
• Implications for direct service providers, supervisors and organizations who provide services those with disabilities.
Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

- World Health Organization
Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

-World Health Organization
Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive and impart information related to sexuality;
  - sexuality education;
  - respect for bodily integrity;
- choose their partner;
  - decide to be sexually active or not;
  - consensual sexual relations;
  - consensual marriage;
  - decide whether or not, and when, to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

- World Health Organization
People With Disabilities Are People

1. Most want emotionally and/or sexually intimate relationships
2. Most want to feel desirable
3. Lack of access to comprehensive sexuality education
   • Additional needs to have disability-relevant issues addressed.
Interactions With Providers

1. Provider discomfort
   • Not asking/addressing
   • No comfortability/confidence

2. Treatment like ‘whole person’

3. Importance of normalization
Disability Shapes Experience

1. **Attributions of incompetence**
   - Forcible sterilization
   - Pregnancy termination
   - Removal of children
   - Termination of parental rights
   - Unwanted celibacy (consent)
   - Institutionalization – temporary and long-term

2. **Stigma**
   - Self-stigma
     - Interferes with confidence, perceptions of relationship options
     - Changes in sexual function result in further self-stigmatization, ‘broken’
   - LGBT+ clients face double stigma
     - Higher rates of identification, esp. among some sub-populations
Disability Shapes Experience

3. Loss

• Rates of divorce and separation 2-3x higher for SMI than general population
• Loss of one’s sexuality
  • Institutionalization
    • Relationship interference and institution rules & norms
• Medication
• Effects of illness
• Loneliness
Impacts of Institutionalization

1. Lack of privacy = ‘sex where you can’
   • Punishment for sexual expression
2. Lack of access to condoms, etc.
3. Situational same-sex sexuality
Risk

1. Higher rates of sexual assault
   • Increased dependency
   • Misinterpretation of intent/boundaries
   • Unsafe environments
   • Reports of assault dismissed as psychosis or misunderstanding

2. Engagement in problematic behaviours
   • Misinterpretation of intent/boundaries
   • Lack of socially acceptable options

3. Rates of HIV & Hepatitis C are higher
   • Unprotected intercourse, multiple partners, sex trade, and IDU are common
Implications

1. Support in developing a positive sexual self-concept
2. Support in establishing, sustaining, and maintaining intimate relationships
3. Support in having safe, pleasurable sexual experiences
4. Support in navigating obstacles to the above
Implications

1. Information and Education
2. Skills Training
3. Coping Strategy Enhancement
4. Access to Talk Therapy & Support Groups
The birds and the bees are for everyone:

The sexual selves of people with disabilities

Alie Kriofske Mainella, PhD.
Counselor Education and Counseling Psychology
Marquette University
Introduction

About me: Alie Kriofske Mainella
Road to sexual health education and counseling for people with disabilities
Consider your own road to sexual health learning
Albert Bandura’s Social Learning Theory

1977; 1986
Simon and Gagnon Social Script Theory

Cultural

Inter-personal

Intra-personal

1973
Figure 2. Modified Model for the Construction of Individual Sexuality in People with Cerebral Palsy

NB: Sub-scripts may differ based on individual circumstances (context) but major schema and their salience in individual
What does this mean for the outcomes of people with disabilities?

• Contraception
• STIs
• Prevention
• Healthy relationships
Contraception
Barriers to care: contraception and disability

• **Physical access**
  • Need for accessible examination tables for people with paralysis, multiple sclerosis and cerebral palsy, etc..
  • Women with chronic mental health conditions are largely of reproductive age and may experience access barriers in insurance, education and treatment access

• **Communication access**
  • Information in Braille and Sign language interpreters
  • Information that is easy to understand for people with intellectual disabilities or mental health issues
Medications interacting with contraception

• People with mental health disabilities are underserved in terms of contraception and sexual health care
• Interactions between prescribed medications and birth control
• People with seizure disorders taking medications that induce cytochrome P450 enzymes can decrease the efficacy of hormonal contraceptive methods, necessitating higher doses for effective contraception.
STIs
Vulnerability to STIs and Disability

• People with disabilities are more vulnerable to STI and HIV transmission because of lack of education, lack of access to health services and public transportation, and undermined social opportunity

• One study suggests that 8% of adolescents with disability were exposed to an STI compared to 3% of adolescents without disability (2011)

• People with spinal cord injury may be less able to notice symptoms of an STI,

• People with intellectual disabilities, chronic mental health conditions or traumatic brain injury may not remember to or know to use condoms/other contraception
Women with disabilities do contract STIs and HIV

STI contraction can occur because of

| Access barriers | Attitudinal misconceptions | Lack of awareness of risk |

Treatment causes challenges to practitioners because of confusion around symptoms,
Sexual Abuse Prevention
1 in 5 people with disabilities experience sexual violence

That’s more than TWICE the rate of people without disabilities

Lund & Vaughn-Jensen, 2012
Ableism

People with disabilities seen as:

• Less human
• Less valuable
• Less visible
Healthy Relationships

And relationships with self
Sex education for people with spina bifida and cerebral palsy: A study

1. Does the receipt of sexual health education in adolescence impact sexual health knowledge in adulthood?

2. Do sexual health variables (sexual health education experience, sexual knowledge, and sexual self-concept) predict subjective well-being?

3. Does sexual knowledge predict sexual self-concept?

4. Does sexual self-concept mediate the relationships between social support and subjective well-being?  
   Kriofske Mainella, 2019
Sample Demographics

- Disability
  - Cerebral palsy (30.8%)
  - Spina Bifida (64.4%)
- Average age 35 (SD=10.3)
- Caucasian (83.7%)
- Female (61.5%)
- Relationship Status
  - Single (54%)
  - In a relationship (46%)
- Education
  (Bachelors or higher 44%)
- Living situation
  (51% living independently with someone)
- Attended public high school (88%)
- Received sexual health education (89%)
- Received majority of sexual health education formally (75%)
- Satisfaction with sexual health education
  - Informal (Yes 42%)
  - Formal (Yes 53%)
Results
Do sexual health variables (sexual health education experience, sexual knowledge, and sexual self-concept) predict subjective well-being?

Demographic factor of relationship status (being in a relationship) significantly and positively predicted subjective well-being.

Satisfaction with formal and informal sexual health education positively and significantly predicted subjective well-being.

Higher sexual self-concept scores also positively and significantly predicted subjective well-being.
Contributions to overall life satisfaction

- In a relationship: 16%
- Satisfied with sexual health education: 8.9%
- High scores in sexual self-concept: 4.4%
  (High confidence, self-efficacy and optimism & low anxiety)
FINAL THOUGHTS

• People with disabilities are sexual

• Sexuality is a natural part of being human

• Sexuality is all encompassing

• People develop a sexual script naturally based on their culture, experiences and behavior (and resulting reactions)

• Being approachable and ask-able with this topic is a great step
Thank you
Any questions?
What YOU Can Do
The Fundamentals:
It’s What We Do All The Time

✓ Assessments, goal-setting, documentation, recovery/treatment plans, referrals, consultation, ongoing service/treatment...

✓ Shift to new needs, populations, areas and demands.

✓ Develop and rely on professional discipline when getting ready for the next adventure.
A Professional Discipline to Approaching Service Changes

1. Do our own personal inventory.

2. Do our own professional inventory.

3. Consult, engage and collaborate with supervision and peers.

4. Identify and integrate applicable evidence-based practices.
1. Do Your Own PERSONAL Inventory

- The impact of overlaying our unexamined or established values, expectations and beliefs on those we serve.
- Being watched and assessed by the people we serve.
- We all have preconceptions, assumptions, and preferences.
- Knowing our own limitations, and
- Have established resources for those we serve when it is best for us to opt out.
2. Do Your Own PROFESSIONAL Inventory.

1. If there are aspects or areas that are unfamiliar or uncomfortable, how do we get more skills, training, supervision.

2. Assessing our own professional scope of practice and taking steps to expand it where possible, needed or helpful.

3. Do we know, and are we comfortable with the language.

4. Figure out what we need to do this well and effectively.

5. What skills or information is needed to effectively adapt interventions for the specific people we serve?
3. Consult & Collaborate: Supervision and Colleagues

So many things to consider with supervision and as a team:

- Program expectations and scope of practice
- Ongoing supervision & support
- Identify appropriate tools.
- Working with contracted providers and residential facilities
- Different team member responsibilities and expertise
- Where and how to document
- Resources and collaborators within the organization & community
- Staff training
- Identify important issues: Examples - Consent, relationships, parents & guardians, community resources, potential safety concerns.
- Community values and expectations
- Advocating for change within the larger organization
4. Identify & Integrate Applicable Evidence-Based Practices

A Case for Motivational Interviewing

1. Developmental Change

2. The Spirit of Motivational Interviewing

• Development of a trusting partnership where the provider accepts the person exactly as they are.

• Working from a frame work where each of us is the absolute experts on ourselves. Providers acknowledge the person’s expertise about themselves.

• The practitioner works to evoke, bring out, each person’s hopes and what they value which may be internal motivation for change.
The Spirit of Motivational Interviewing

• Providers acknowledge each person’s autonomy, including their right to not change or to make decisions the provider, or others, might see as less than ideal or potentially problematic.

• The service provider provides acceptance, compassion, support.

• The provider and works to let the person know that they are trying their best to accurately and compassionately hear what they are.

  • Adapted from *Motivational Interviewing* 3rd Edition
Advice: Take It or Leave It

1. Shift the focus of services to what effects change and personal developmental growth. Not ☑ Sexuality
2. Already know the basics about each person’s hopes, priorities, goals.
3. Always ask permission.
4. Start with open-ended questions.
5. First, find out what they already know.
6. Work hard to really hear what they are telling you.
7. Let them know you are working hard to hear by making your “best guess” at what they are telling you.
8. Ask them to consider how their needs line up with their values and priorities.
What can YOU do?

Find ways to make your facilities more welcoming and safe.
What Can You Do? Start Conversations

• Bring an article, resource or topic for discussion to a team meeting.
• Develop ways that are comfortable to you, and those you serve, to ask and talk about sexuality.
• Look at your office walls and add something inclusive.
• Start a file of resources and tools.
• When your organization is asking for ideas on areas of need, speak up.
• Find, and attend, training, webinars, conferences. Better yet, get on a planning committee.
• Encourage conferences & webinars to include Sexuality & Disability.
• Tell the people you serve that you are looking to build knowledge in this area and ask about their experiences with services.
Keep Going

• Gain knowledge about sexual health and disability to be more adequately prepared to discuss these issues with clients

• Disability severity and sexuality
  • If you work with clients with disabilities, you can help them understand how their sexuality is impacted by their disability as a part of containing the effect of disability (Wright, 1983)

• Most importantly, be approachable and ask-able should the topic come up
Advocating for Change In Programs, Agencies & Organizations

1. Think systemically. Work to understand each level’s roles and responsibilities.
2. Consider how significant changes in services have been integrated in the past.
3. Acknowledge and respect the larger organizational potential areas of concern.
Be Encouraged. Choose to be Involved.

Changes Are Already in Motion
References


References (cont.)

References (cont.)