DISABILITY CULTURALLY COMPETENT SEXUAL HEALTHCARE

Linda R. Mona, Ph.D. (she/her/hers)
Licensed Psychologist
Inclusivity Clinical Consulting Services

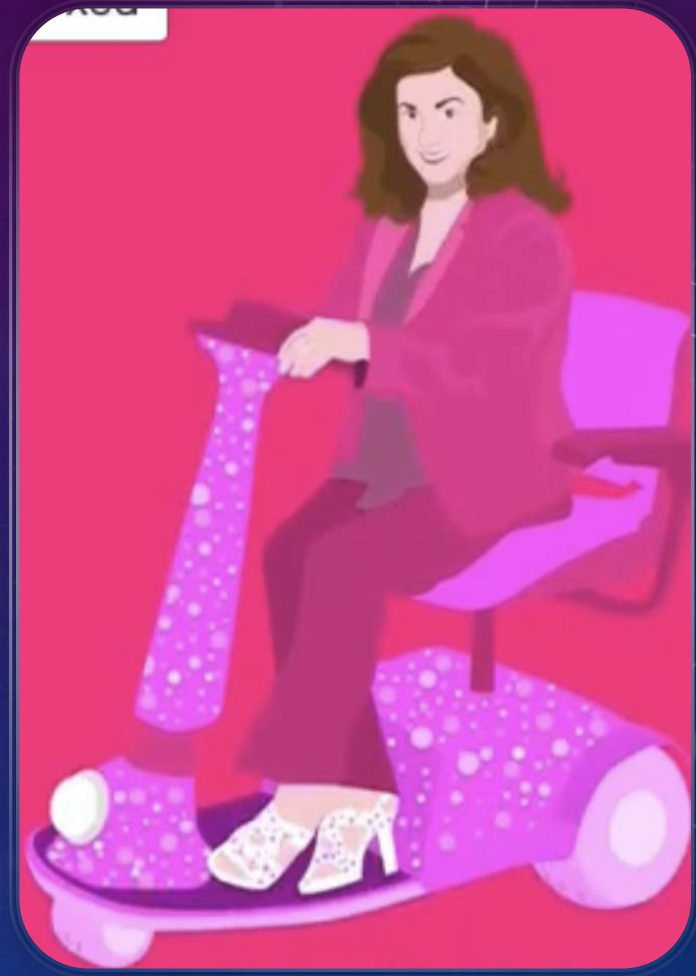
SETTING THE TONE!

DR. LINDA MONA

- Image description
- Description of my appearance
- Self-Identification
    - Authentic bio
- Pronoun preference (she, her, hers)

DR. LINDA MONA

- Image description
- Why are descriptions important?
- Encourage you all to use descriptions today

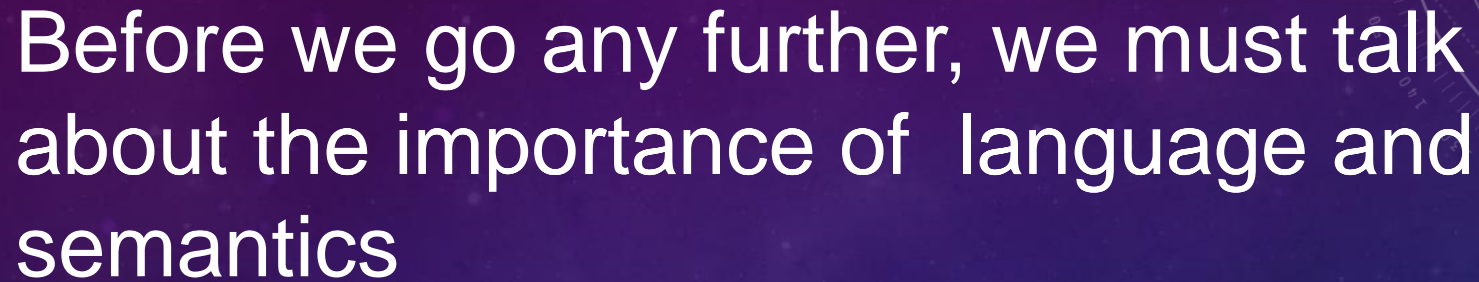


AGENDA

- Disability diversity
- Semantics
  - Language
- Definitions of disability
- Disability cultural competence and humility
- Disability and sexuality
- Sexual health
- Assessment and Treatment
  - Disability
  - Sexuality
- Psychologists' Call to Action

WHAT IS IMPORTANT TO YOU?

- Reality is…. Cognitive, behavioral, emotional and physical components of trauma/injury/disability can affect all levels of life and our jobs as psychologists
- How much do you care about disability? Race/Ethnicity?
- Why should you care?
- Fearful of the topic?
- Ethical responsibility?
- If you don't know or get it…. not to worry.



How do you decide what to use and how to use it?

It depends!

Person-first...
Prefix first...
Doesn't matter.

DISABLED.

#SayTheWord

But, not so great at showing people how to do it and why it is important

DISABILITY DIVERSITY SELF-ASSESSMENT

- Definition
    - Assessment or evaluation of oneself or one's actions and attitudes of one's performance at a job or learning task considered in relation to an objective standard
- What is the objective standard for understanding disability?
    - Consider your professional role
        - Ask the question

GET COMFY!

DISABILITY EXERCISE: “IF YOU EVER..”

(WILLIAMS, 2012)

Ask Yourself……………… “if you ever”:

- Avoided a person with a disability?

DISABILITY EXERCISE: “IF YOU EVER..”

(WILLIAMS, 2012)

Ask Yourself……………… “if you ever”:

- Felt scared when encountering a person with a disability?

"IF YOU EVER……."
(WILLIAMS, 2012)

Ask Yourself……………… "if you ever":

- Felt sad when encountering a person with a disability

“IF YOU EVER…….”
(WILLIAMS, 2012)

Ask Yourself……………… “if you ever”:

- Felt inspired by a person with a disability

DISABILITY EXERCISE (WILLIAMS, 2012)

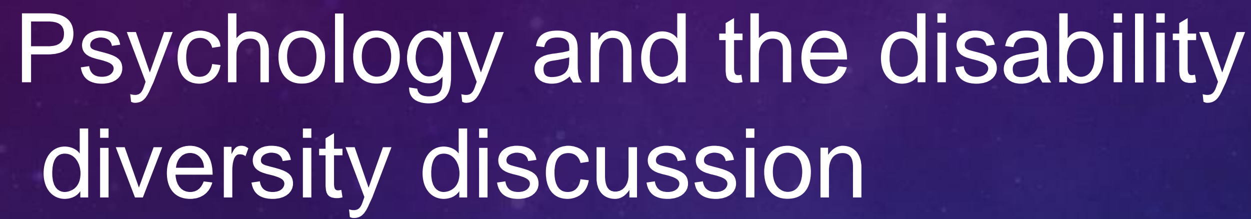
- Consider yourself and important identities
- Consider how your world informed you about disability
  - Who were your informants?
  - What were the messages?
- What is your relationship with disability now?
  - Have one, know someone, co-worker

ASK YOURSELF…..

- When you think of disability, what comes to mind?

Normalization of disability

- Falls under the umbrella—why couldn't I have seen this when I was a kid?


Psychology and the disability
diversity discussion

DEFINITION OF MULTICULTURALISM AND DIVERSITY

- Multiculturalism/diversity encompasses multiple dimensions that comprise a person's identity including race, ethnicity, language, sexual orientation, gender, age, disability, class status, education, religious/spiritual orientation, and other cultural dimensions (American Psychological Association, 2002)

- Multiculturalism: Quality or condition of a society in which different ethnic and cultural groups have equal status and access to power but each maintains its own identity, characteristics, and mores (American Psychological Association, 2015)

DISABILITY FACTS!

- Fifteen percent of the global population has a disability, with the number of people increasing each year (WHO, 2011).
- The traditional terms 'disability' includes:
  - medical, physical, psychological, and cognitive conditions and/or impairments that impact a person's engagement in one or more major life activities (WHO, 2010; CDC, 2020).

CONCEPTUALIZATION OF DISABILITY

- Disability Definition
  - “Umbrella term” for functional limitations that result from the relationship between physical differences and the contextual environment (WHO, 2011, p. 4)

CONCEPTUALIZATION OF DISABILITY

HOW WE THINK ABOUT THE CONCEPT

- Disability Definition
  - Complex interaction among medical, social, environmental, and political factors (WHO, 2011)

DISABILITY RIGHTS ARE CIVIL RIGHTS

WHAT IS THE ADA?

- Federal statue designed to prevent discrimination and to promote equal opportunities for people with disabilities
- Provides civil rights protection for people with disabilities in the areas of:
  - Employment
  - Public services
  - Public and private transportation
  - telecommunication services

DEFINITIONS OF DISABILITY:
MEDICAL/FUNCTIONAL DEFINITION

- ADA definition of disability
  - Physical or mental impairment
  - Limits one or more major activities
  - Has a record history of an impairment
  - Regarded as having an impairment

HOW WE MAKE SENSE OF DISABILITY COMES FROM MANY SOURCES

(ORTO & POWER, 2007)

CONCEPTUAL MODELS OF DISABILITY

Models of Disability	Disability is…	Society's Response
Moral Model	• Test of faith or divine retribution for sin • Family/individual is responsible for disability • "Cure" lies in faith	• Charity •Prayer •Punishment/Blame •Forgiveness
Medical Model (Normalcy Model)	• Bodily defect or abnormality •"Defect" needs to be cured in order for the individual to function in society •Primary model used today	• Fix it •Correct it •Eliminate it or prevent it •Eugenics? •End of Life Decisions? •Adapt and Adjust •"Blend" and / or "Pass" •Psychology: Facilitate acceptance
Minority Model (Social or minority group model)	• Defined and maintained by socio-political factors •Disability is socially constructed	• Empowerment/Social justice • Promote voices from within • Not about us without us • Disability is Natural and Normal • Presume Competence • Psychology: Facilitate disability identity formation and pride!

DISABILITY WITHIN A SOCIAL CONTEXT

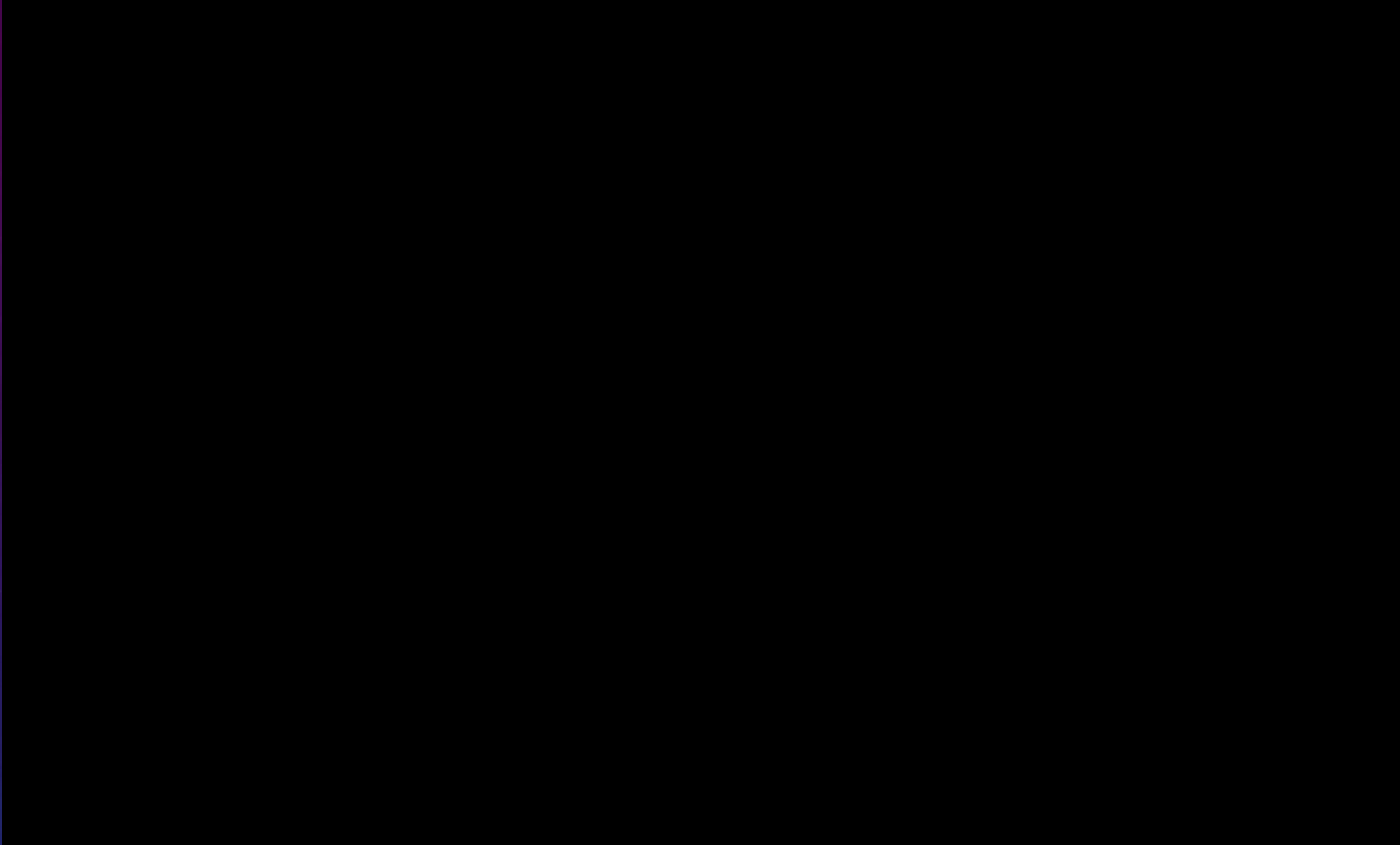
Hint: This topic is important when it comes to sex……

SOCIETAL BELIEFS ABOUT DISABILITY (OLKIN, 1999)

- Stereotypes
- Attitudes
  - Negative and/or heroic
- Factors that affect attitudes toward disability
  - Perceiver characteristics
  - Characteristics of PWD
  - Characteristics of disability
  - Characteristics of context

"That quote, 'the only disability in life is a bad attitude', the reason that's bullshit is ... No amount of smiling at a flight of stairs has ever made it turn into a ramp. No amount of standing in the middle of a bookshelf and radiating a positive attitude is going to turn all those books into braille."

— Stella Young



Inspirational porn

ABLEISM DEFINED

- Ableism refers to the beliefs, practices, and polices that tolerate and promote the unequal treatment of people based on actual or presumed disabilities (Campbell, 2008a).

ABLEISM

- "Ableism is connected to all our struggles because it undergirds notions of whose bodies are considered valuable, desirable, and disposable." (Mingus, 2010)

BUT….

How do psychologists typically think about disability?

AND…..

What do disabled clients/patients really want to say to healthcare providers?

IMPORTANT CONSIDERATIONS: DISABILITY IN HEALTHCARE (BENSON, 2016)

- Patient/Provider relationships
  - Data suggests that relationship with provider influences health behaviors
  - Research shows that patients prefer providers who are confident, empathic, humane, forthright, respectful, and human
  - How is “Patient-Centered” care inclusive of disability?
- Treatment planning should be programmatically “accessible”

PERSONAL PERSPECTIVES
ANDRE 2012

- “Disabled folks know primary care providers aren’t disability specialists. Take the attitude of “I don’t know but I’m willing to do the work to find out.” Don’t expect your disabled patient to educate you on everything about their disability”

- “Although we *are* generally interesting people, don’t make us into your fascinating case study on disability. Check your curiosity”

PERSONAL PERSPECTIVES

ANDRE (2012)

- “Don’t bring in your team of residents or interns to check out a rare diagnosis or “exceptionally functional” or “special” case without permission first. Don’t objectify us.”
- “Don’t assume every health issue is disability-related or that disability equates to poor health. Health promotion and disease prevention are just as important for disabled people as everyone else.”

HOW DO WE BECOME
DISABILITY CULTURALLY
COMPETENT PROVIDERS?

AMERICAN PSYCHOLOGICAL ASSOCIATION POLICY STATEMENT: EVIDENCE-BASED PRACTICE

"Evidence-based practice in psychology is the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences."

CULTURAL COMPETENCE MODEL

- Balcazar et al.(2009) identified four key components
  - Critical awareness
  - Knowledge
  - Skills development
  - Practice and application

ADDRESSING FRAMEWORK
(HAYS, 2008)

- Age
- Disability (Developmental)
- Disability (Acquired)
- Religion
- Ethnicity
- Socioeconomic Status
- Sexual Orientation
- Indigenous Heritage
- National Origin
- Gender

DISABILITY CULTURE: CORE VALUES
(GILL, 1995)

- Acceptance of human variation
- Matter-of-fact orientation towards assistance
- Tolerance for the unpredictable, living with uncertainty
- Disability humor
- Skills in managing multiple problems
- A sophisticated future orientation
- A carefully focused capacity for closure in interpersonal communication
- A flexible adaptive approach to tasks

**** Values vary based upon nature of disability

DISABILITY CULTURAL COMPETENCE & HUMILITY

- Disability Cultural Competency
  - Disability isn't just a separate culture, it's another planet
  - Disability is both a social experience and a difference lived in the body, brain, and/or mind
    - Disability culture is not simply a layer of experience that can be easily separated out of interactions

INTERSECTIONAL CULTURAL HUMILITY VS. CULTURAL COMPETENCE

DOES IT HAVE TO BE EITHER OR?

BUCHANANAN, RIOS, AND CASE (2020)

Table 1. Intersectional cultural humility vs. cultural competence.

Comparison domains	Intersectional cultural humility	Cultural competence
Purpose	• Deepening awareness of a complex array of many structures and systems and increasingly accurate analysis their impact on lived experiences.	• Improving interactions across individual people (e.g., understanding variations across cultures in norms regarding direct eye contact).
Identity dimensions of focus	• Considers interactions across all identity dimensions.	• Prioritizes racial and ethnic identities.
Conceptualizing culture	• Encourages transcendence toward understanding that culture is far more complex and acceptance that aspects of the situation may be beyond our understanding or reach.	• Assumes culture can be measured by observable traits and behaviors among group members.
Ecological foci	• Identifies socio-cultural mechanisms and social institutions as critical factors influencing individuals, groups, and communities and these influences change over time.	• Often focuses on individual-level influences, interactions across dyads or small groups, and does not incorporate temporal changes.
Group member experiences	• Are dynamic over time and vary across people, requiring that practitioners attend to intersections of race/gender/ social class/ etc., and how these inform both client and practitioner perspectives.	• Are static over time and uniform across people. • Assumes essentialist traits in groups of people that can reduce attention to variability across members of the group.
Attention to power	• Expects consistent analysis of individual and group power, how power impacts systems and constrains individual people.	• Ignores power generally, whether between people and/ or social practices, policies, institutions, culture.
Practitioners' reflections on their privilege	• Requires deep and persistent reflection on one's personal privileges and biases. • Encourages recognition of "epistemic privilege" and how their specific cultural perspective influences practitioner assumptions and formulations.	• May encourage, but does not require that practitioners be accountable for their own privilege in relationship to their clients.
Learning process and timeline	• Learning must be a life-long endeavor, understanding that subjective experience is shaped by social context, which makes it ever-changing.	• One can achieve expert status through the careful observation and learning about other groups of people and then their learning process is complete.
Mastery goal	• Assumes mastery may never be achieved. • Encourages acceptance that we will all continue to make mistakes and therefore must remain open to learning.	• Assumes an end goal of expertise of other cultures and at that point no further learning is necessary.

CULTURAL COMPETENCE/ HUMILITY AND DISABILITY

- Conceptualize PWD using the minority model (Artman & Daniels, 2010)
  - PWD are like other minority groups
    - Shared history of discrimination, oppression and intolerance
  - PWD are also different than other cultural groups
    - Issues related to environmental and programmatic accessibility
    - Medical symptoms related to their disability

BREATHE AND REFLECT

DISCOMFORT IN THE "DISLIKE" OF DISABILITY (MONA, CAMERON, & CLEMENCY CORDES 2017)

- We must embrace the possibility of accepting non-preferred aspects of the disability experience as non-preferred, rather than expecting people with disabilities to risk inauthenticity in the name of self-acceptance

DISCOMFORT IN THE "DISLIKE" OF DISABILITY (MONA, CAMERON, & CLEMENCY CORDES 2017)

- We need to make room for a layered experience of disability identity that neither idealizes nor pathologizes essential aspects of adaptation to disability
- This allows for a more truly empathic response to patients with disabilities, which may enhance patient provider alliances
- Adaptation to disability is not a circumscribed, finite process

5 Wheelchair Exercise

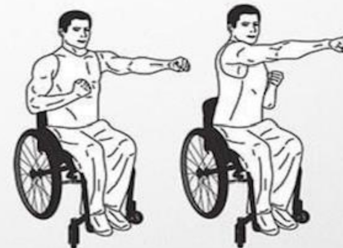
20 chest expansions

20 side arm raises

10 dives

10 raised arm circles
5 clockwise / 5 counterclockwise

20 overhead punches



20 punches

motion

OR, JUST……,

- Close your eyes
- Look out your window
- Blink
- Do something different

SEXUALITY, DISABILITY, AND
EVERYTHING THAT COMES WITH IT!

DISABLED AND SEXUAL. DEAL WITH IT!

TRIGGERED

DISABILITY AND SEXUALITY

- The most difficult dialogue
- Joining of two under discussed life experiences
  - PWD at times have questionable human status
  - Right to experience pleasure

GET COMFY!

SEXUALITY SELF-ASSESSMENT:

- Have you ever struggled to accept your own body and/or sexuality?

SEXUALITY EXERCISE: "IF YOU EVER.."

- Ask yourself… "If you ever":
  - Had feelings that you did not accept your own body as being attractive or sexual?

SEXUALITY EXERCISE: “IF YOU EVER..”

- Ask yourself… “If you ever”:
  - have recognized that your apprehensions, negative inclinations, and possible prejudices about sex have influenced your perceptions of others’ sexuality?

SEXUALITY EXERCISE: “IF YOU EVER..”

- Ask yourself… “If you ever”:
  - have found yourself having an automatic judgement towards somebody’s body that does not meet “traditional standards” of attractiveness

DISABILITY AND SEXUALITY PERSONAL BIAS ASSESSMENT QUESTION (MONA, CAMERON, AND CLEMENCY CORDES, 2017)

What are my opinions about people with disabilities having sex?
What prevents me from asking questions about sexuality and disability?
When did I first think about people with disabilities being sexual?
What were the messages that I received about sexual attractiveness and disability?
Are there certain types of disabilities/chronic health conditions that I think preclude being sexual?
Are there certain types of disabilities/chronic health conditions that I might find sexy or attractive?
Do I find myself feeling pity, projecting my own fears, or reflexively admiring people with disabilities?
How might broader cultural views and judgments that may not be prominent in other areas of healthcare service provision subtly influence my thinking with regard to sexuality and/or disability (e.g., ageism, gender roles, ethnic/racial or other group stereotypes)?
Do I judge certain types of disabilities that are seemingly beyond a person's control (e.g., an injury sustained in a car accident) differently than ones that I perceive having been under the person's control (e.g., an injury that may have involved substance use or reckless behavior)?
How would I feel about being sexual if I had a disability?
How would I feel about being sexual if my partner had a disability?

CHECK YOURSELF: SEXUAL PERMISSION SYSTEMS

- Who
- When
- Where
- Under what circumstances
- Your guidelines and expectations for yourself and others

WHO DEFINITION: SEXUAL HEALTH (2006)

- "Sexual health is the integration of the somatic, emotional, intellectual, and social aspects of sexual being"
- But what if there is limited access to…
  - sexual education/information
  - pleasure
- How does disability fit in to this space?

SEXUALITY AND DISABILITY: FREQUENT CLINICAL THEMES

MONA (2002)

- Feeling nonsexual and undesirable
- How and where to find partners
- Disclosure of disability status
- Sexual functioning
- Body image/appearance
- Sexual positioning
- Communication barriers
- Knowing how body works

SEXUAL HEALTH ASSESSMENT:
USING DISABILITY CULTURAL
COMPETENCE & HUMILITY

ASSESSMENT CONSIDERATIONS

- Where will the assessment take place?
  - Degree of privacy
  - Inpatient or outpatient status
  - Long-term or residential care settings
- What is the climate of the facility?
- What is the role of the clinician?
- What barriers exist for the Client/Patient?

ASSESSMENT QUESTIONS

- What questions do you ask?
- Psychological and sexual history
  - Sexual behavior and activity
  - Sexual attitudes and beliefs
  - Ways that disability has affected self- perceptions and experiences
    - **How has your disability/chronic health condition affected your sex life?**
- Sexual relationship history
- Create treatment plan and prioritize goals

ASSESSMENT: INCORPORATION OF SEXUAL WELL-BEING

- Interview questions that capture sexual enhancement and satisfaction
  - What is the most satisfying about sexuality/intimacy?
  - What types of sexual activities do you enjoy?
  - What areas of your intimate life would you like to enhance?
  - Please describe your values about intimacy and sex

ASSESSMENT: SEXUAL CONSENT CAPACITY

- What is the cognitive and functional status of the client?
  - Sexual consent capacity
    - Ability to voluntarily make a reasoned decision whether or not to engage in sexual activity

ASSESSMENT OF SEXUAL CONSENT CAPACITY (LICHTENBERG & STREZPEK, 1990)

- Patient’s awareness of relationship
- Patient’s ability to avoid exploitation
- Patient’s awareness of sexual risks

Sexual rights and disability

CREATING AN INTIMACY WELLNESS PLAN

- Absurd idea?
- Have you thought about these issues in your own life?
- Encourage patients to have “The conversation!”
  - How would you want your partner or other family members to make decisions?

Ethics and Assessment: Sexuality and End of Life

- Milieu attitudes
- Administration and policy
- Tools
    - Screen during regular assessment
  - Attend to clarifying values
    - Intimacy at the end of life
    - Spectrum of intimate behaviors preferred
    - Potential barriers of setting

SEXUAL HEALTH INTERVENTION:
ADAPTIVE SEXUAL EXPRESSION

INTERVENTION:
MIND BODY APPROACHES

- What meta frameworks do we use?
  - Cognitive Behavioral Therapy
  - Acceptance and Commitment Therapy
  - Mind/body Interventions

INTERVENTION:

- Issues to keep in mind when treatment planning
  - Cognitive genital dissociation
    - When is sexual activity over?
  - Disability sexuality prejudice/rejection
  - Redefining roles as lovers and partners
  - Changes in sexual self-esteem

INTERVENTION

- Issues to keep in mind when treatment planning
  - Body looks different
  - Scarring
  - Ambulate/Move differently
  - Think/Feel differently
  - Hardware (Wheelchairs, braces, leg bags, trachs)
  - Pharmacological side effects
  - Clothes, clothes, clothes!

WHAT WORKS!
(MONA, 2002)

- Meeting partners through friends
- Meeting partners online
- Discussing disability early within the relationship
- Knowing how your body works
- Talking directly to your partner about disability function and limitations within sexually activity
- Discussing partner-related stigma

ACCESSIBLE SEXUAL PLEASURE

SEXUAL PRODUCTS AND ACCESSORIES

- Sex is supposed to be fun….just in case you forgot
- Experiencing pleasure and sexual activity are ADLs… But that's not all
- Finding a product and/or equipment that works
  - Sexual products as adaptive equipment
  - Condition type
  - Functional limitations and abilities
  - Comfort and desire for product

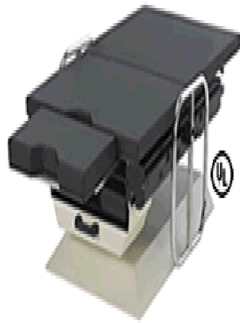
Queer disabled podcast: Pleasure and fun

OTHER GOODIES:
SEXUAL HEALTH, FERTILITY, PREGNANCY, &
PARENTING

OBSTACLES AT HEALTH CARE FACILITIES

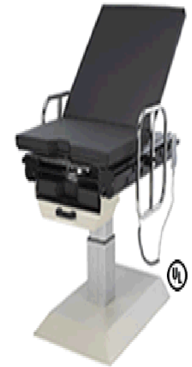
- **Accessibility of facilities**
  - OB/GYN tables
  - Room size for privacy
  - Accessible bathrooms
- **Access to non-prejudicial providers**
  - **Fertility/Pregnancy**
- **Knowledgeable professionals**

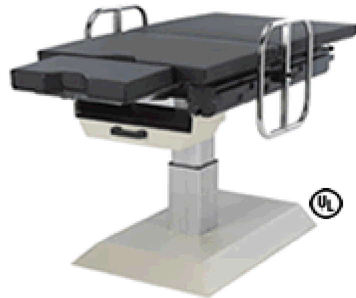
WELNER TABLE



- 650 pound capacity
- hi-lo 18" to 39"
- 54"x 32" top surface
- 10" foot extension
- radio-translucent tops

- powered back section
- powered pelvic section
- pendant control
- comfort pad
- anti-static surface





- integral accessory rails
- 18"x 18" side rails
- full foot/calf boot
- storage drawer

*** 2 YEAR WARRANTY / UL APPROVED ***

OTHER PRACTICE IMPLICATIONS

ADDRESSING ABLEISM WITHIN SEXUALITY INTERVENTIONS

- Understanding our own ableism and other ism's
  - Explicit and implicit (Hwang, 2021; VanPuymbrouck et al., 2020)
  - Individual, systemic, and programmatic levels
- How might we be inadvertently engaging in ableist practices that could be impacting our disabled clients?

CASE EXAMPLE

- Jill is a 21-year-old, Black, cisgender woman that presents to therapy; she is seeking help for depression and anxiety, as well as feelings of loneliness, poor sleep, difficulties with memory, and chronic pain. She reported that her symptoms began after a car accident, which resulted in a moderate traumatic brain injury at 19 years old. When she completed rehabilitation to address her physical symptoms and returned to college, everyone told her that she "looked normal" and "great." She didn't know how to take these "compliments," because on the inside, she felt like a different person. Specific to her cognition, Jill noticed that she felt overwhelmed and easily distractible, especially when multiple people spoke at once. For the most part, she keeps quiet about her cognitive complaints, because when she shares her experiences, she hears things like, "Join the club. No one can concentrate in our generation!" When she mentions her concerns to her parents, they say things like, "Oh honey, just try and focus on the positive. Just be grateful that you aren't disabled. You can still live independently and go to school. We'd say that you're doing pretty well compared to other people." Over time, she reported feeling more anxious, depressed, and lonely. When asked about her treatment goals she stated, "I just wish I was fixed, so I could be normal again."

CASE EXPLORATION

- What are some of the ableist messages in this case example?
- How has Jill internalized ableism?
- As a mental health provider, what model of disability do I subscribe to and how does it show up in my language and notes/reports?
- As Jill's mental health provider, how have I explored my explicit and implicit personal and institutional biases surrounding Jill's cultural identities?
- How might I challenge and address (a) misconceptions of disability and (b) personal and institutional biases?
- How might I address sexual/relationship intimacy issues

D-AT	Content	Notes
I	Current Disability Status	• Moderate TBI • Poor sleep, chronic pain, depression, anxiety, loneliness, and poor concentration
II	Developmental History	• Received messages about her disability from people unfamiliar with TBI
III	Models of Disability	• "I just wish I was fixed, so I could be normal again." • Likely Jill subscribes to a medical model
IV	Disability and Other Demographics	• 21-year-old woman, cisgender Black woman • Works full-time and denied financial stressors • Lives independently
V	Disability Culture and Community	• Does not identify as a person with a disability • Does not know anyone else with a TBI
VI	Social Interactions	• Notable for numerous & consistent messages that invalidate her disability • Receives pejorative messages about disability
VII	Effects of Microaggressions	• Invalidation of her disability and experiences • Anxiety, depression, & loneliness • Never sought assistance for some of her complaints (e.g., concentration), because others normalized and or invalidated her reports
IX	Intimacy	• Not interested in dating at the moment • Because her family and friends don't listen to her experiences, she feels less close to them. She feels lonely and has become quieter.

CALL TO ACTION:

Self-Assessment

- Consider personal and professional areas of growth
- Read disability and sexuality literature
- Consume disability information
- Become familiar with disability issues and rights
- Consider gaps in training
- Promote the presence of disability at all levels of your profession

CALL TO ACTION:

- Accessibility insures inclusivity (programmatic barriers, alternative formats)
- Deconstruct environmental and social barriers (social environment)
- Break the silence about disability among colleagues
- Be willing to be wrong and redirected

QUESTIONS & COMMENTS

INCLUSIVITY CLINICAL CONSULTING SERVICES

www.inclusivityconsulting.com

www.facebook.com/inclusivityconsulting

Linda R. Mona, Ph.D.

drlindamona@inclusivityconsulting.com

310.594.9605