Americans with Disabilities

- 38 million Americans living with disability
- 18.5 million with Cognitive and/or Ambulatory Disabilities between ages 18 and 65.
- All of which are sexual beings!

MISSION

- To empower people with disabilities to make informed decisions regarding their sexual and reproductive health and to provide a better understanding of the need for sexual education and resources as related to the disabled community.
Yes, disabled people can and do have sex, relationships and families!

Today’s Topics

- Health Services & Sex Education
- Dating, Intimacy & Relationships
- Functionality & Sex Aides
- Sexual Abuse & Consent
- Fertility, Pregnancy & Birth

Change and Awareness is Necessary to Enhance & Promote Full-Life Recovery following Traumatic Injury

2014 STUDY BY DYER & NAIR

- 97% of professionals believed that the topic of relationships and intimacy should be discussed, but only 36% actually addressed these issues with their clients.
Sexual abuse & consent

Sexual consent is actively agreeing to participate in a sexual activity before being sexual with someone.

Consent is about communication

- Sexual consent is actively agreeing to participate in a sexual activity before being sexual with someone.

- Both people must agree to sex — every single time — for it to be consensual.
A person is guilty of criminal sexual conduct if the person engages in sexual penetration or contact and the actor knows or has reason to know that the victim is mentally incapable, mentally incapacitated, or physically helpless.

The term "sexual assault" means any unwanted, non-consensual sexual contact of any kind (including kissing) obtained through the use of force, threat of force, intimidation, or coercion.
According to 2017 Bureau of Justice’s
- Persons with disabilities are twice more likely to be sexually assaulted than people without a disability.
- 18% of all rapes and sexual assaults are reported to be committed by strangers, which means that most of these crimes are committed by someone the victim knows, is close with or related to.

Who can people with disabilities turn to, talk with in private and express themselves freely without fear of backlash?

SEXUAL HEALTH SERVICES

The sexual well-being of people with disabilities is extremely important and it’s time we expressed that need!
Care needs to be managed by a team of healthcare professionals to oversee the physical and psychological needs of their patients.

Life After TBI

TBI is known to cause changes in thinking, behavior and body function which alters the way a person experiences and expresses their sexuality.

Changes to sexual behavior after TBI could include erectile problems, reduced libido, the inability to orgasm, and the reduction in frequency of sex.

Everyone is entitled to express their sexuality, receive appropriate important information regarding their sexual health and receive proper guidance.

ACCESS TO HEALTH SERVICES
Sexuality is one of the most complex aspects of life but the sexual lives of people with disabilities have been disregarded and stigmatized. As a result, sexuality as a form of pleasure and an expression of love is not taken into account or even recognized for individuals with disabilities.

Research has shown that TBI and SCI survivors report significant changes that impact relationships which can include behavioral and emotional changes, cognitive and physical changes, difficulties communicating, role changes from significant other to caregiver and changes in self-esteem, as well as, self-identity.

Men
- Fertility
- Erectile problems
- Reduced libido
- Inability to orgasm
- Reduction in frequency of sex

Women
- Pregnancy and Birth
- Assessable doctors' offices
- Birth control options dwindle significantly because of hormones and other ingredients included in pills, patches, injections or implanted devices.
- Women with disabilities often need specialists to handle their pregnancy and birth.
Sexual expression is influenced by cognitive and emotional processes and is dependent on functioning anatomical and physiological systems, in other words, our brains control our sexual organs and responses.

Before resuming sex with a partner, boyfriend, girlfriend or spouse, talk about it with your doctor or therapist and be guided by their advice.

Make sure you are clear and talk with your mate about your expectations, fears and feelings, including consent.

Communication is key!

You may need to change your relationship’s love-making activities which can be normal sex and mutual masturbation.

To increase intimacy, concentrate on building confidence in your relationship by offering love or affection, complementing and saying nice things to each other and celebrating big and small occasions.
The Role of the Therapist

Sexuality is an integral part of the human experience and contributes to an individual’s quality of life, satisfaction and overall health.

(Crooks & Bauer, 2013)

KEY DEFINITIONS

World Health Organization:

Sexual health:
“...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health 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”

Multi-Disciplinary Approach

SEXUALITY RESOURCE EDUCATION CENTRE MB
Occupational Therapy Framework Defines:

**Sexual Activity as an**

"Activity of Daily Living"

**Managing Intimate Relationships as an**

"Instrumental Activity of Daily Living"

AOTA, 2014; Estes 2014

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**Who Should be Addressing Sexuality?**

- Psychiatrists
- Primary Care Physicians
- Urologists, Gynecologists, Endocrinologists
- Behavioral Health (Psychologist / Psychiatrists)
- OT / PT / Speech Language Pathology
- Nurses
- Social Workers
- Fertility Specialists
- Certified Sex Counselors or Therapists

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Why An Interdisciplinary Therapy Team?

My Advice to other disabled people would be, concentrate on things your disability doesn’t prevent you doing well, and don’t regret the things it interferes with. Don’t be disabled in spirit as well as physically.

— Stephen Hawking

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Research Findings

- Improved quality of life (Sale et al., 2012)
- May mitigate depression, anxiety, & self-esteem issues (Hough et al. & Barbonetti et al., 2012)
- Avoid general health symptoms associated with sexual dysfunction (Khak et al, 2016)
- Improved knowledge
- Provision of support
- Reduce feelings of isolation
- Reduce unevenness of services provided
Direct and Indirect Injury Effects Impacting Sexuality and Wellness

Physical/Sensory Barriers
- Motor Function (paralysis, spasticity, coordination)
- Medical Complications
- Medication and Side Effects
- Fatigue
- Sensory Tolerance and Changes
- Various Levels of Pain
- Bowel/Bladder Challenges
- Seizures
- Endocrine Abnormalities Leading to Fluctuating Hormone Levels and Effects

Cognitive Barriers
- Attention
- Memory
- Awareness
- Language and Communication
- Decreased Initiation
- Impulsivity
- Regulation of Behaviors and Emotions
- Planning and Time Management

Emotional and Behavioral Barriers
- Personality Changes
- Adjustment and Loss
- Depression
- Anxiety
- Difficulties with Perception and Expression of Emotions
- Apathy
- Disinhibition
- Lability
- Self Esteem
### Social Barriers

- Self-Esteem
- Decreased Social Contact
- Relationship Changes
- Role Status
- Socioeconomic Status
- Transportation Obstacles
- Residential Obstacles

Goldwin, 2015

### Predictors of Lower Sexual Functioning

- Greater injury severity measured by Post Traumatic Amnesia duration
- Lower Levels of Independence with ADLs
- Mood/Psychological Adjustment
- Higher Levels of Depression
- Lower Self-Esteem
- Shorter time post injury
- Age and Age of Injury (Younger adults fare best 24-49 years old)

Stahvyk et al., 2013

### Challenges / False Beliefs

Therapist's Perspective

### Staff Barriers to the Provision of Sexuality in Rehabilitation

- Levels of Staff Discomfort
- Perception of Expertise Elsewhere
- Client Readiness
- Staff Attitudes

Egleder, K.L., 2017
Clinical Model for Sexuality and Wellness

- **Model:**
  - PLISSIT
  - Intentional Relationship Model
  - Mindfulness

PLISSIT Model (Permission Limited Information-Specific Suggestions-Intensive Therapy approach) (Levin 1978) and the Therapeutic Use of Self through Intentional Relationship Model (Taylor 2008) and Mindfulness (Kabat-Zinn 2011)

Clinical Assessment for Sexuality and Wellness

- **Assessment:**
  - Occupational Profile
  - Quality of Life After Brain Injury Scale (QoLIBRI)
  - Brain Injury Sexuality Questionnaire (BIQS)
  - Index of Sexual Satisfaction (ISS)
  - Sexual Quality of Life Questionnaire (SQoL)
**Timing and Approach**

- Understand “client’s” definition of Sexual Health
- Initiate conversation early on:
  - Normalize sex as one of many ADL’s
  - Provide client options
    - Identify who they can talk to
    - Identify options and resources
- Don’t make assumptions as providers
  - “Not ready to talk about it”
  - “Shouldn’t they be focused on rehab”

**Thoughts to Consider**

**Environment:**
- (Social & Physical Conditions)
  - Access to the Activity and Influences on the Quality of Satisfaction with Performance
  - Social Groups, Family Dynamics
  - Living Situation (Physical & Social Needs of Involved Parties)
  - Access to (Health Provisions, Education and Resources)
  - Media Influences
  - Expectations of Spouse, Significant Other, Guardian, Friends, Caregivers

**Context Surrounding the Person:**
- Interrelated conditions that are within and surround the person and influence performance
  - Trust, Responsibility, Emotional Availability, Attitude, Sharing and Understanding, Empathy, Self-Esteem, Past Relationships, Body Image
  - Personal Factors (Age, Gender)
  - Temporal Factors (Stage of Life, Time of Day, Duration of Activity)
  - Virtual Contexts (Interactions such as Simulated, Real Time, Near Time Situations absent of physical content)
  - Cultural & Religious Beliefs
Occupation: (Act of/Activity)
- Spending Quality Time
- Care for Each Other
- Using Safe Practices
- Self-Care
- Sharing Through Feelings
  - Emotional Intimacy
  - Intellectual Intimacy
  - Physical Intimacy

Environment: (Social & Physical Conditions)
- Access to the Activity and Influences on the Quality of Satisfaction with Performance

Context Surrounding the Person:
- Interrelated conditions that are within and surround the person and influence performance

Question 3: Have You Talked To A Professional (Doctor, Therapist, Counselor) About Sex?
- Yes: 44%
- No: 33%
- Interested: 24%
- Not Interested: 0%

Question 6: Do You Know Where To Go For Sexual Education And Resources?
- Yes: 45%
- No: 55%
Question 7: Have You Ever Had Questions Or Concerns Regarding Sexual Health?

- 74% YES
- 26% NO

Intimacy Survey

Question 9: Would You Feel Comfortable Talking To A Health Professional About Your Sexual Needs / Concerns?

- 28% YES
- 72% NO

Intimacy Survey

Question 10: Has Anyone Addressed Your Sexual Functionality Or Ability To Engage In Intimate Relations?

- 47% YES
- 53% NO

Intimacy Survey

DISABILITY & SEXUALITY

NO BIG DEAL
(Sex & Disability)
Sexual Functioning 1 year after a Traumatic Brain Injury: Findings from a Prospective Traumatic Brain Injury Model Systems Collaborative Study.


Rape, Abuse & Incest National Network (RAINN). Retrieved from https://serc.mb.ca/sexual0health0info/sexuality/sexuality0wheel/

Estes, J. (2002). Beyond basic ADLs: Sexual expression is an important but often overlooked activity of daily living. Rehabilitation, 28:164–170.
