

DISABILITY & SEXUALITY

Let's Talk About Sex ...
After Brain Injury



Kim Austin-Baker
Barbara Hill, OTR/L

www.amyabaker.net

DISABLED SEX

Americans with Disabilities

2015 Census Data



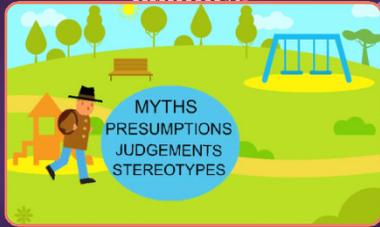
- ▶ 38 million Americans living with disability
- ▶ 18.5 million with Cognitive and/or Ambulatory Disabilities between ages 18 and 65.
- ▶ All of which are sexual beings!

■ Disabled Population ■ Cognitive or Ambulatory

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.



“Breaking the Mold”

Sex Re-Education



CONSENT

TRUST SUPPORT SEXUAL ASSAULT

DRUGS AND A

SAFETY ADVICE TALK TO US

YOUR RIGHTS

Sexual Abuse & Consent

Consent is about communication

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

<p>Ongoing</p> <p>Anyone can change their mind about what they're interested in doing, anytime.</p>	<p>Freely given</p> <p>Saying yes without pressure or manipulation.</p>	<p>Specific</p> <p>Saying yes to one act (i.e. kissing) doesn't mean you've said yes to others (i.e. oral sex).</p>
<p>Informed</p> <p>Not deceiving or lying. For example, if someone says they'll use a condom and then they don't, there isn't full consent.</p>	<p>con • sent</p>	
<p>Enthusiastic</p> <p>It's about wanting to do something, not feeling like you have to or should, do something.</p>		

IF IT'S NOT

CLEAR

IT'S NOT CONSENT

Both people must agree to sex — **every single time** — for it to be consensual.

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!



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

(S)EXPLORING DISABILITY

DATING, INTIMACY & RELATIONSHIPS

Dating, Intimacy & Relationships



- ▶ 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.

Dating, Intimacy & Relationships

- ▶ 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.

Fertility, Pregnancy and Birth

<h4>MEN</h4> <ul style="list-style-type: none"> ▶ Fertility <ul style="list-style-type: none"> ▶ Erectile problems ▶ Reduced libido ▶ Inability to orgasm ▶ Reduction in frequency of sex 	<h4>WOMEN</h4> <ul style="list-style-type: none"> ▶ Pregnancy and Birth <ul style="list-style-type: none"> ▶ 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.
---	--



The Disabled Body: Functionality and Pleasure

- ▶ 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.**

The Disabled Body: Functionality and Pleasure

- ▶ 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!**
- ▶ Remember to not put too much pressure on yourself, focus on pleasure and not technique
- ▶ You may need to change your same old lovemaking style and experiment with other sexual activities which can include oral sex and mutual masturbation.
- ▶ To increase intimacy, concentrate on boosting the romance in your relationship by offering lots of affection, complementing and saying nice things to each other and celebrating big and small occasions.

From a Survivor's Perspective
to a Therapist's Perspective

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)

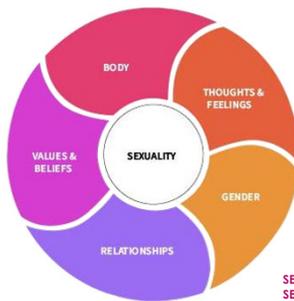


KEY DEFINITIONS

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"



SERC
SEXUALITY RESOURCE
EDUCATION CENTRE MB

Multi-Disciplinary Approach



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

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

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

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

Goldwin, 2015

Cognitive Barriers

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

Goldwin, 2015

Emotional and Behavioral Barriers

- Personality Changes
- Adjustment and Loss
- Depression
- Anxiety
- Difficulties with Perception and Expression of Emotions
- Apathy
- Disinhibition
- Lability
- Self Esteem

Goldwin, 2015

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)

Stolwyk et al., 2013



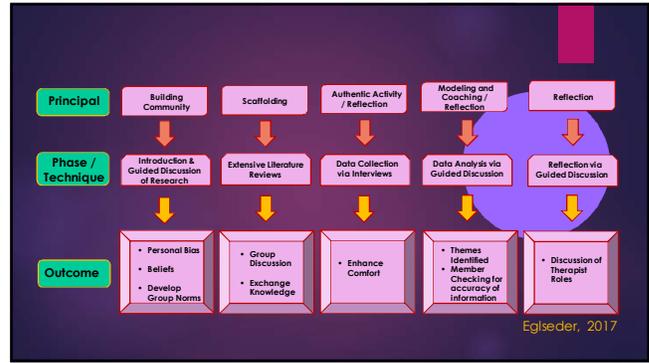
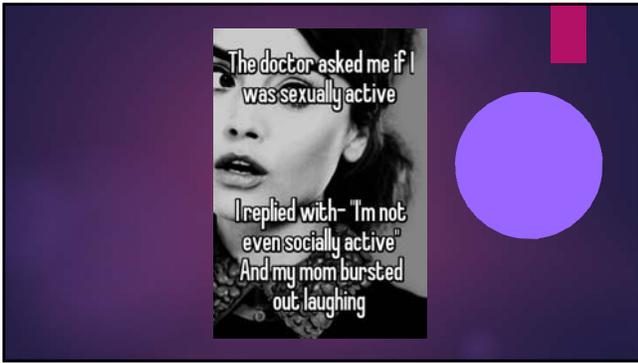
Challenges / False Beliefs

Therapist's Perspective

Staff Barriers to the Provision of Sexuality in Rehabilitation

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

Eglseder, 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) (Annon 1976) and the Therapeutic Use of Self through Intentional Relationship Model (Taylor 2008) and Mindfulness (Kabat-Zinn 2011)

Clinical Assessment for Sexuality and Wellness

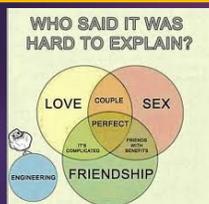
- Assessment:
 - Occupational Profile
 - Quality of Life After Brain Injury Scale (QoLIBRI)
 - Brain Injury Sexuality Questionnaire (BIQS)
 - Index of Sexual Satisfaction (ISS)
 - Sexual Quality of Life Questionnaire (SQoL)

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”

Ellis, 2015

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

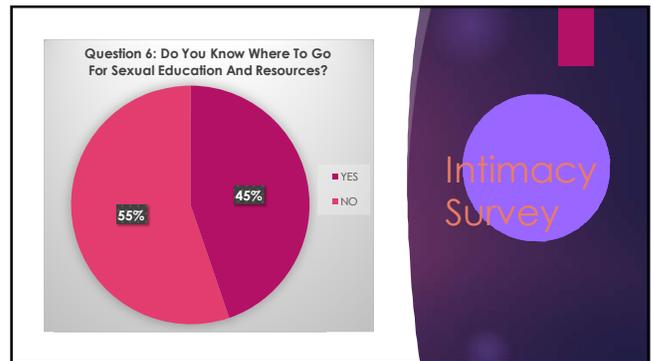
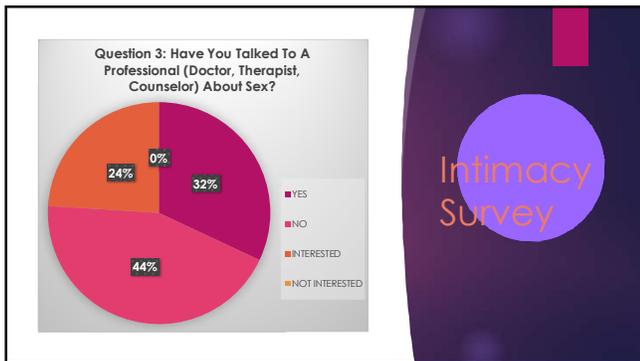
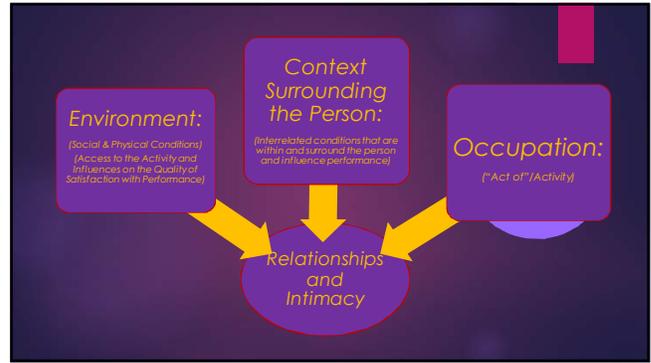
Context Surrounding the Person:

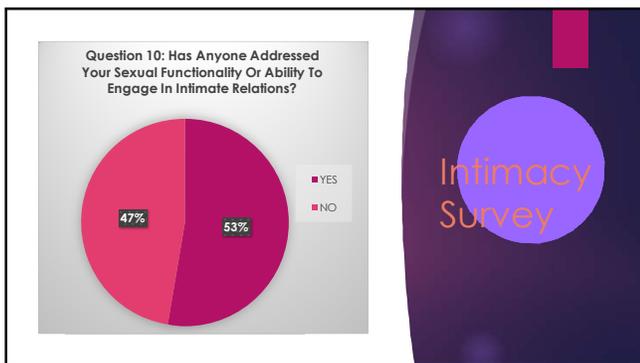
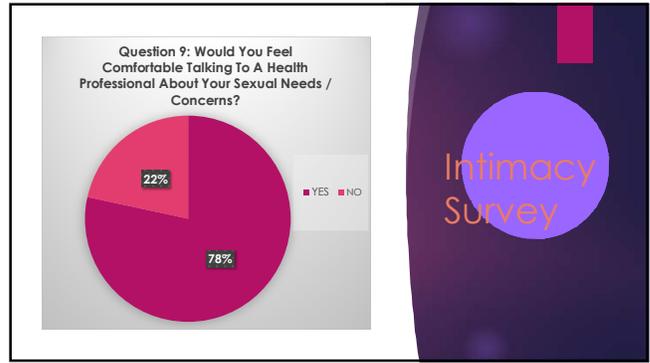
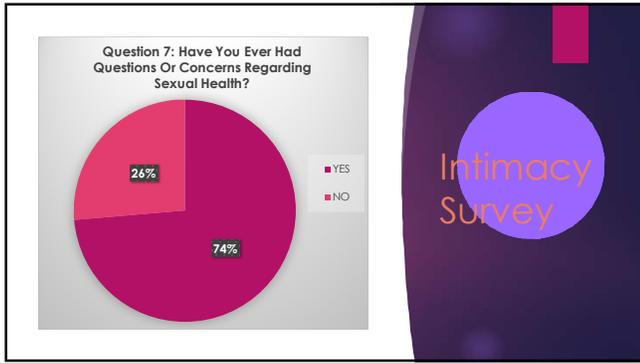
(Interrelated conditions that are within and surround the person and influence performance)

- * 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





DISABILITY & SEXUALITY

NO BIG DEAL
(SEX & DISABILITY)

