THE ESSENTIAL BRAIN INJURY GUIDE

Rehabilitation Philosophy & Cultural Competency
Section 6

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This training is being offered as part of the Brain Injury Alliance of Connecticut’s ongoing commitment to provide education and outreach about brain injury in an effort to improve services and supports for those affected by brain injury.
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ACBIS Exam Study Outline

- Rehabilitation Philosophy
  - Models of disability
  - Tenets of person-centered approaches
  - Effects of improvement in self-awareness
  - Components of therapeutic relationships
  - Latrogenesis
  - Extenders
  - Assistive Technology for cognition

Keep an eye out for this
ACBIS Exam Study Outline

- Cultural Competency
  - Definitions of culture, sociorace, universalism, and multiculturalism
  - Types of intelligence
  - Racial and ethnic issues

- Gender/Sexuality
  - Differences in injury and outcomes between males / females
  - Primary and secondary causes of sexual dysfunction
  - The concept of benign neglect

- Aging
  - Diagnosis of dementia
  - Predominant factors of disability
Rehabilitation Treatment
Philosophies and Approaches
Learning Objectives

- Identify the most common service delivery model
- Distinguish between process and progress
- Articulate the extender model
- Understand concept of person centered care
- Discuss treatment models and how these models impact treatment provision
- Explain the principles and virtues of a therapeutic relationship
- Describe the interdisciplinary approach
- Understand person first language
- Understand the utility of assistive technology for cognition
Models of Disability as Foundations for Rehabilitation

**Biomedical**
- Treatment methods are concerned with changing the individual (i.e., getting better).

**Functional**
- Intervention methods are aimed at adapting the function of the individual for meaningful participations.

**Environmental**
- Intervention is sought to address both the physical and social environments of the individual.

**Sociopolitical**
- The goal for the individual is inclusion, civil rights, and equal social status.
Biomedical or Medical Model

- Used to understand most health conditions but does not lend itself well to psychiatric or cognitive conditions
- Uses experts to define characteristics, prognosis, and treatment
- Two dimensions; normal vs pathological (health vs illness)
- Deficits are identified, implying there is something wrong with the person with disability; treatment concerned with “getting better”
- Promotes exclusion of therapeutic services after medical stabilization has occurred
- Promotes concepts such as treatment plateaus and maximum medical recovery
Functional Model

- Most individualized model and serves as the basis for “person centered” care
- Intervention methods are aimed at adapting the function of the individual for meaningful participation (including assistive technology)
Environmental Model

- The environment can cause, define, and exaggerate disability
- Rehabilitation addresses both physical and social environments
- Prejudice, discrimination, and stigma are part of the environment and not an inherent part of disability
- One of the most appropriate models for conceptualizing psychological disabilities
- This perspective provided for social movements that resulted in:
  - Supported employment and supported living
  - The Americans with Disabilities Act
Sociopolitical or Minority Group/Independent Living Model

- Inclusion, civil rights, and equal social status are the goals
- Highlights society’s responsibility for accommodating people with disability
- Recognizes prejudice and discrimination are causal factors in disability
Moral or Religious Model

- Additional model which is not useful as a foundation for rehabilitation
- Views disability as a result of sin, evil, or a character flaw
  - People with visible disabilities were devalued immediately
  - People with invisible or hidden disabilities like mental illness were isolated and excluded
Brain Injury Rehabilitation Is A Process..

The mere acknowledgement of brain injury rehabilitation as a process encourages the individual participating in rehab to own the process and identifies clinicians and family members as tools, supports, and allies in the process.

This is an important and empowering concept for successful brain injury rehabilitation.

Process VS Progress - need to consider & frame in less traditional ways

- progress implies end point, fix or restore what is wrong, short term tx, funding, relationships
- Process implies life altering event, lengthy/comprehensive tx. recognizes long term, complex personal, social, financial consequences
Person-Centered Care

- Empowers individuals to guide the rehab team to focus on their priorities, values, and desired outcomes

- Maintains that:
  - The person served can be trusted to lead their own lives
  - Provider’s attitude and therapeutic relationship are major factors in outcome
  - All people have capacity for self direction and intervention is most effective when requested
Person Centered Care; the Challenge of Impaired Self-awareness

- Frontal lobe injury impacts self-awareness

- Anosognosia is defined as “inability to recognize deficits or problem circumstances caused by neurological injury”

- Self-awareness is defined as “the capacity to perceive the ‘self’ in relatively ‘objective’ terms while maintaining a sense of objectivity”

- Impaired self-awareness can exist at all points during the rehab process and can be permanent for some individuals

- Importance of treatment - people who improve one level in self awareness are 30 times more likely to be in the successful treatment outcome group

Emergent awareness: person lacks immed. Awareness of how a “deficit” adversely impacts functional abilities
Ethical Principals that Guide Therapeutic Relationships

Are there challenges in maintaining these principals?
Virtues That Guide Therapeutic Relationships

Are these always Easy to adhere to?

- Integrity: Act on deeply Held values
- Prudence: Act with discernment/ in good faith
- Compassion: Act & follow through On promises/commitments
- Trustworthiness: Act & follow through On promises/commitments
- Respectfulness: Act with discernment/ in good faith
- Personal dignity: Are these always Easy to adhere to?
Critical Components to Facilitating and Maintaining Therapeutic Relationships

Person First Language
Person centered care starts with use of person first language such as “Individuals Living with a Brain Injury.”

Humaneness
Empathy, warmth and respect are powerful ways for treatment providers to facilitate and maintain therapeutic relationships.

Communication
Communication patterns (verbal and non-verbal) of treatment providers should reflect how they would want to be treated.

Questions vs. Directives
Questions like “Can you please help?” empowers persons served by providing choice, whereas “Come help me” does not.

Non-Judgmental Approach
A non-judgmental approach to care is reflected in positive attitudes and consciously practicing “no blame” when caring for others.
Interdisciplinary Rehabilitation
Rooted in functional approach to rehab.

- Physiatrists
- Neurologists
- Neuropsychiatrists
- Neuropsychologists
- Behavior Analysts
- Psychotherapists
- Social Workers
- Case Managers
- Occupational Therapists
- Physical Therapists
- Speech and Language Pathologists
- Respiratory Therapists
- Recreation Therapists
- Nurses
- Substance Misuse Counselors
- Vocational Counselors
- Direct Support Providers

Extender Model
trained staff provide therapy, supervised by licensed or certified clinical staff

Iatrogenesis
Inadvertently induced negative effects or problem caused by physician, therapy, or med/rehab setting
Post Acute Brain Injury Rehab (PABIR)

Residential

Need longer term intensive rehab.
Challenging behavior
Unable to manage independently
Lack adequate supports in community

Without PABIR, iatrogenic behavior
Problems may emerge

iatrogenic – inadvertently induced
Disease/unfavorable circumstance caused by treatment or setting
Assistive Technology for Cognition (ATC)

Assistive technology for cognition ranges from low-tech to high-tech systems.

Integration of ATC is a practice standard for mild memory impairment AND practice guideline for mod-severe memory impairment

Mainstream and generic devices whenever possible – Why?
Learning Objectives

- Be able to discuss how culture plays a role in rehabilitation
- Be able to articulate the concept of cultural diversity as a core principle in rehabilitation
- Be able to integrate cultural differences into neurorehabilitation through the utilization of the Biopsychosocial Model
- Be familiar with the Racial/Cultural Identity Development Model (R/CID)
- Be able to describe good ways of creating a climate that is welcome to those from culturally diverse backgrounds
Multiculturalism

- Multiculturalism has been called a social-intellectual movement that promotes cultural diversity as a core principle and insists on equality and respect of all groups.

- There is disparity in the use of health care services:
  - Only 1 in 3 people who need mental health services accesses them and minorities in particular underutilize these services.

- In order to understand how culture impacts the rehabilitation process, we must understand the concepts that form the basis of culture.
Ethnicity

Ethnicity relates to national origins, which then provides information as to the customs, norms and languages that are shared across generations.

Race

Race has historically been used to group people based on biological or physical traits, but is now conceptualized by multiculturalists as sociorace.

Sociorace

Sociorace recognizes the social and historical aspects of a group of people, providing information about customs, norms and social aspects of the group.

Culture

Culture is defined as any group that shares a theme or issues. This can include language, food, clothing, music, art, dance, behavioral norms, shared values, and shared worldviews, to name a few.
Racial/Cultural Identity Development

- This model highlights the progression of an individual in establishing his or her cultural experiences
- The model assumes valuation of the majority cultures (conforming to the majority), and progresses toward valuation of one’s own culture as well as the dominant culture
- As a brain injury specialist it is important to take into account the level of assimilation and acculturation that each person has in regard to their culture as well as the majority culture
Worldview

- The way in which a person approaches their everyday experiences is based on their culture.

- Worldview is the way in which people perceive their relationships to nature, institutions, other people, and things.

- World views (such as moral standards, human-nature interface or group relations) as well as basic abilities (such as cognition, thought and behavior) are multidimensional.

- It is important not to apply one’s own worldview or universal expectations of shared abilities to the rehabilitation process - it fails to take into account each individual’s cultural and personal norms, values and customs.

Rehabilitation specialists must ask themselves:

What cultural experiences has each person I serve had in life and how has this affected them?

Universalism – assumption that human characteristics common to all members of the species produce psychological givens with culture influencing their devp. and display.
Constructs of Intelligence

- There are different constructs of intelligence, each of which speaks to a different ability that can be impacted by culture
  - **Academic (analytical) intelligence** – is used to signify the person’s ability to solve problems in academic (classroom) settings
  - **Practical intelligence** – is used to signify the person’s ability to solve problems in everyday settings (practical life problems)
  - **Social intelligence** – a distinct set of skills necessary in order to successfully navigate the environment.
  - **Emotional intelligence** – important in terms of human experiences

- Cross cultural psychology has documented extensive cultural disparity in human cognition, thought and behavior
  - Viewing these constructs as universal to all cultures, worldviews, etc., is counter to person centered care

Westerners/Europeans – think analytically   Asians – think holistically
<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Example</th>
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<tbody>
<tr>
<td>Biological</td>
<td>Behavior is influenced by physiological and genetic makeup.</td>
<td>A patient may have a genetic predisposition to diseases such as diabetes or depression.</td>
</tr>
<tr>
<td>Cognitive – Affective</td>
<td>Thoughts and feelings (i.e., our psychological state) can impact our behavior (i.e., our physical state).</td>
<td>Stress can impact many bodily systems including musculoskeletal, respiratory, cardiovascular, endocrine, gastrointestinal and reproductive – thus, high levels of stress may negatively impact a patient’s overall health or impede recovery.</td>
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<tr>
<td>Social – Interpersonal</td>
<td>Social relationships can impact our behavior.</td>
<td>A patient attempting to remain sober is ridiculed by friends for not hanging out and drinking with them, resulting in isolation and fueling his depression/drinking vicious cycle to a greater degree.</td>
</tr>
<tr>
<td>Social – Institutional</td>
<td>Behavior is influenced by interactions with social institutions.</td>
<td>A patient experiences discrimination within a large hospital system, resulting in distrust of physicians and caregivers, and reduced adherence to medical advice.</td>
</tr>
<tr>
<td>Cultural</td>
<td>How we behave is impacted by values, practices and beliefs that are culturally ingrained.</td>
<td>A patient of Chinese descent nods when asked by his white physician if he will follow the dietary guidelines provided and take the prescribed medications they reviewed; the physician presumed the nod meant the patient was in agreement with the diet guidelines and the medication; in reality, the patient nodded solely out of deference and had little intention to vary from his current regimen of traditional herbs and acupuncture.</td>
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Creating culturally diverse treatment settings

Incorporating Cultural Diversity into Treatment Environments

- Encourage use of first language in environments with others who also speak that language
- Provide bilingual and multilingual signs
- Provide books and materials written in various languages
- Provide opportunities for people from similar groups and languages to gather when possible
- Encourage people to write contributions to newsletters or other venues in their first language
- Invite volunteers from different groups to act as resource people and invited speakers
- Display pictures and objects from a variety of cultures
- Celebrate holidays and events from different cultures allowing opportunities for education
### Practical Guidelines when Providing Care

**Always be mindful of person’s background and worldview**

<table>
<thead>
<tr>
<th>Always practice the golden rule: Treat others as you would like to be treated</th>
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<tbody>
<tr>
<td>Think before speaking and avoid using labels</td>
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<td>Always ask before giving assistance</td>
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<td>Avoid showing pity or being patronizing</td>
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<td>Challenge the person to succeed</td>
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<tr>
<td>Encourage ‘I will’ instead of ‘I will try’</td>
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<tr>
<td>Promp a response instead of using force</td>
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<tr>
<td>Do ‘with’ instead of do ‘for’ or do ‘to’</td>
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Teach individuals living with brain injury to ask themselves proactive questions such as “What is the best way to respond to a situation?”

Provide auxiliary aids – interpreters, note takers, written materials

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Aging With A Brain Injury
Learning Objectives

Understand the concepts of cognitive aging

Be able to explain the issues of older adults with TBI
Aging - Long Term Consequences TBI

- Injury incurred earlier in life, now aging OR injury incurred as an older adult
- Patterns of cognitive issues, functional limitations, and recovery issues are different
- Ground level falls in elderly people have greater mortality and severity of injury is less predictive
Institute of Medicine (IOM)  
Long Term Consequence

- This long term outcome information came from studies that looked at individuals with TBI from 1 year to 20 years post injury.

- Disability was related to cognitive, behavior, and personality changes rather than physical changes.

- Caregiver burden increased over time and was related to cognitive and behavior issues.

- Complications include unemployment, under employment, lack of residential options, limited social integration, and need for supervision.
Long Term Consequences of TBI

• Causal Relationships
  • Penetrating TBI = seizures, premature death
  • Mod-severe TBI = seizures

• Sufficient Evidence of an Association
  • Mod TBI = dementia of Alzheimer’s type, parkinsonism, endocrine dysfunction
  • All TBI = depression, aggressive behavior, irritability

• Suggestive Evidence of an Association
  • mTBI W/loss of consciousness = parkinsonism
  • mTBI W/loss of consciousness = dementia as above

To date, there is no definitive link between brain injury and future risk of Alzheimer’s disease (AD). Repeated injury was related to a trend for greater risk of AD.
TBI and Dementia

- To date, there is no definitive link between brain injury and future risk of Alzheimer’s disease (AD)
  - Repeated injury was related to a trend for greater risk of AD

Dementia DX = must include functional limitations in daily life due to the cog changes
Aging with Brain Injury: Psychosocial Issues and Physical Aspects

Studies indicate 5-10 yrs post injury, disability factors mostly cog, behavior, personality changes, not physical

Psychosocial
- Rates of depression
- Exacerbation of underlying psy. issues
- Anxiety and PTSD

Physical
- causative
- accelerative
Gender and Sexuality
Learning Objectives

To gain understanding of unique challenges experienced by LGBT individuals with brain injury in the context of rehabilitation

To explain why sexuality after TBI is often ignored or minimized in brain injury rehabilitation

To explain why sexuality after TBI is often ignored or minimized in brain injury rehabilitation

To identify physical, emotional or behavioral, and cognitive factors that may result in sexual dysfunction following ABI

To share an example of the dating and relationship difficulties experienced by a person with TBI

To discuss differences in outcomes for men and women

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Although male TBI outnumber females, little understanding exists about impact on women - very new field of study.
Differential outcomes by gender

- Males with TBI outnumber females with TBI
- Females were observed to have worse outcomes on 85% of the 20 variables studied
- Return to full time work

Bar chart:
- Males: 2
- Females: 1
- Mortality: 1.3x
- Poor Outcomes: 1.6x
- Cognitive Impairment: 1.7x
- Males: 23.6%
- Females: 4.4%

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Psychological Sequela of TBI in Women

- Higher rates of depression compared to men
- Higher rates of PTSD compared to men
- Self-report higher rates of sexual difficulty than men
  - Reported more with mTBI than severe TBI
- Increased symptomology over time
- Complicating factors include a premorbid HX sexual trauma and abuse

Professionals must be able and willing to engage in frank discussion of sexuality post-TBI and have some familiarity with treatment approaches and resources to address these problems.
40-60% report changes in libido, arousal, performance.

Can be compounded by meds.

Brain Injury and Sexuality Research
Brain Injury and Sexuality Research

Neurobiological issues (hormones, neural circuits/connections), medications
Reaction to injury/disability and changes in lifestyle and roles

- Reduced: Sexual Energy Drive Desire
- Reduced: Sensation Orgasm
- Problematic Positioning Movement Pain
- Changed: Body Image Confidence Mood
- Decreased: Ability to Satisfy Sexual Partner

Over 50% men/women report loss of confidence, esteem, and depression
Brain Injury and Sexuality Research

- Hyper-sexuality / disinhibition – frontal lobe damage, not as common as loss of interest
- mTBI - 15% continue to have cognitive or psychological difficulties, reporting that they “feel different”
Injury Impacts on Sexual Intimacy

Sexual intimacy involves diverse brain regions

Temporal lobe: area of limbic system most frequently implicated in mediation of sexual behavior

Hypothalamus/amygdala are located in limbic system – emotions, hormones, and behaviors

Hypersexuality, disinhibition

Frontal Lobe

Temporal Lobe

Limbic System

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Causes of Sexual Dysfunction

Primary Causes of Sexual Dysfunction
- Neuroendocrine Changes
- Hypothalamus & Pituitary Damage

Secondary Causes of Sexual Dysfunction
- Physical Changes (Spasticity, Ataxia, etc.)
- Cognitive Impairments (Attention, Memory Loss, Executive Dysfunction, etc.)
- Emotional & Behavioral Changes (Depression, Apathy, Disinhibition, etc.)
- Other Changes (Marital Dysfunction, Social Isolation, etc.)
Why is sexuality not fully addressed in rehab?

- Persons served have difficulty bringing this problem to the team
- Treatment team does not view it as priority in face of other rehab goals
- Sexual function goals cut across all disciplines

Benign Neglect – staff discomfort in treating certain conditions – without intention of malice
SEXUAL INTIMACY

Women with disability stereotyped as asexual – also have reduced opportunities for intimacy

Intimacy can be viewed in four general domains:

**Psychological**
Self-esteem, awareness, respect, loyalty, openness, commitment and intellectual compatibility.

**Emotional**
Abilities to share emotional needs, communicate affection, share mutual empathy & listen.

**Operational**
Sharing responsibilities, decisions, role expectations, and parenting.

**Shared**
Activities, hobbies, traditions, friends, family and community.

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Lesbian, Gay, Bisexual and Transgendered (LGBT) Issues

- 2%-15% of population is homosexual/bisexual
- LGBT individuals with brain injury face unique challenges that are at times mismanaged or ignored in rehabilitation
  - Benign neglect: staff discomfort and inexperience in treating LGBT patients
  - Two factors that contribute to benign neglect:
    - Heterosexism: an ideological system that denies, denigrates, and stigmatizes any non-heterosexual form of behavior or lifestyle
    - Homophobia: negative or hostile attitude toward non-heterosexual people
Adolescent Sexuality and TBI

Primary challenges often due to the secondary causes of dysfunction and injury to the brain

How do young people and adolescents typically get information about sex?

How does injury and its implications impact this demographic group?
Prevention of Sexual Abuse, Exploitation, and Risk

- Overall cognitive functioning
- Safety skills
- Sexual knowledge
- Understanding of consequences
- Overarching ability to make safe and healthy choices

Balance - competence for sexual consent and protection from hard
Sexual Addiction

- Accessibility
- Affordability
- Anonymity

For persons with few other outlets for successful sexual relationships, the internet can become a consuming world.
Formal Interventions for Sexuality Adults/Adolescents

P (A) LISSIT Model – Foundation for counseling and TX

Permission  Affirmation  Limited Information  Specific Suggestions  Intensive Therapy
Thank You!