



Incapacity, Guardianship (& What To Do Instead)

Julia Hiner, MD

Associate Professor & Fellowship Program Director

Joan & Stanford Alexander Division of Geriatric & Palliative Medicine

Department of Internal Medicine

McGovern Medical School

University of Texas Health Science Center at Houston || UTHealth Houston

Houston, Texas

Disclosures

- None

Objectives

By the end of this session, participants will be able to:

- Compare & contrast the six most common causes of enduring incapacity
- List the major steps involved in assessing decisional & executive capacity in Texas
- Decide when guardianship, emergency removal, less restrictive options, or capacity restoration are appropriate for clients

Capacity

- Decisional Capacity: The ability to engage in an informed discussion illustrating understanding of benefits, risks, alternatives of self-care tasks.
- Executive Capacity: The ability to independently plan & take actions, or coordinate others, to perform steps necessary to complete relevant tasks.
- Must consider short- and long-term beliefs, values, and goals.
- Capacity ≠ Competency

Competency

- Presence of characteristics and absence of disabilities which determines one's ability to participate in a legal activity.
- Ability to meaningfully participate in an attorney's examination and act rationally enough to execute legally recognized action.
- Competency is a legal, not medical, determination.
 - Judge may weigh medical evidence when making this decision (e.g., Certificate of Medical Examination), however.
- Determination of incompetency is termed: *de jure incompetent*.

Incapacity

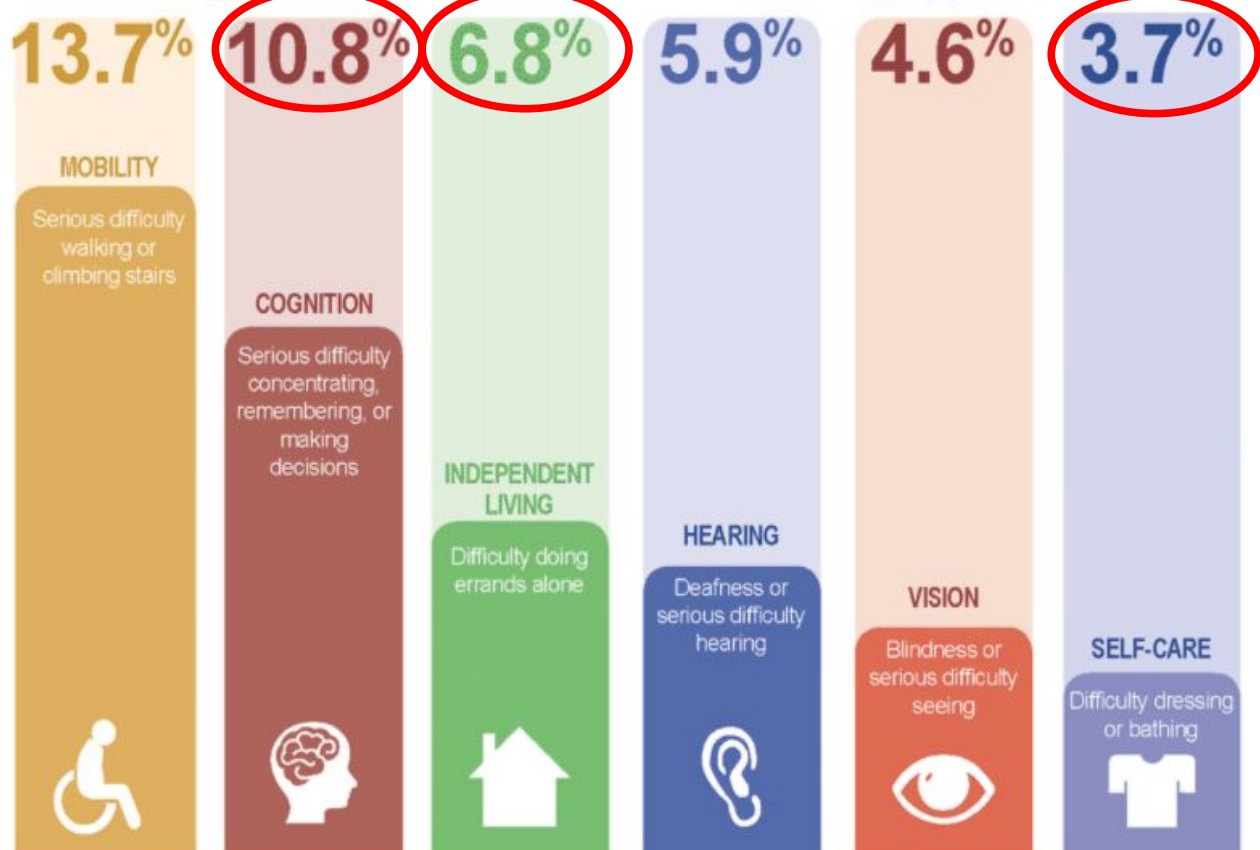
- Texas Estates Code § 1002.017
 - An "Incapacitated Person" is an adult who, because of a physical or mental condition, is substantially unable to: (a) provide **food, clothing, or shelter** for himself or herself; (b) care for the person's own physical **health**; or (c) manage the person's own **financial** affairs.

Disability

- Any bodily or mental condition that causes:
 - Impairment
 - ↑ difficulty completing self-care & other activities
 - ↑ difficulty participating in activities & with people



Percentage of adults with functional disability types



Texas



Capacity Reduction

Transient	Permanent
Acute illnesses	Cerebrovascular Accident (Stroke)
Severe chronic illnesses	Traumatic Brain Injury (TBI)
Delirium	Dementias
Malnutrition	Intellectual developmental disability (IDD)
Medications	Severe psychiatric diseases
Acute substance abuse	Chronic effects of substance abuse

Neurologic: Stroke

- Stroke happens when a blood vessel in the brain:
 - Gets blocked by traveling clots (embolism)
 - Gets extremely narrowed from unstable cholesterol plaque & platelet repair (thrombosis)
 - Leaks or bursts, spilling blood onto brain tissue itself (20%)
- Wide range of symptoms, but classically:
 - Limb paralysis, weakness, numbness
 - Facial droop
 - Slurred or hard to understand speech, difficulty understanding people's speech
 - Loss of balance, dizziness, unsteadiness, incoordination
 - Sudden vision loss
 - Severe headache
 - Confusion

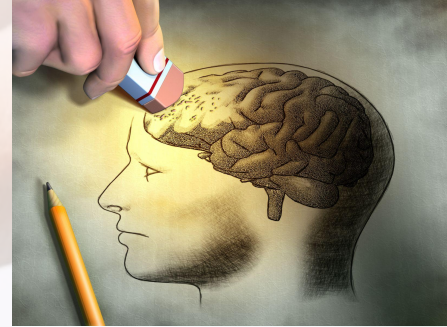
Neurologic: Traumatic Brain Injury

- Alteration in brain function or finding of brain pathology due to external force.
 - Head is struck by or strikes an object (sports)
 - Acceleration/deceleration of brain ("whiplash")
 - Penetrating foreign body or blast force (war, shrapnel)
- Classified as mild, moderate, severe
 - Mild=concussion; severe=vegetative state
- 27-69 million affected **yearly** worldwide
- Economic impact >\$75 billion in USA in 2010
- Deaths: 56,000/year in USA – but survivors with disabilities are the expensive part!



Cognitive: Dementia

- Brain disorder causing:
 - Memory loss / forgetfulness
 - Impaired thinking/reasoning & decision making
 - Psychosocial & language dysfunction
- **KEY:** interference with normal daily function
- 50 million affected by some type of dementia



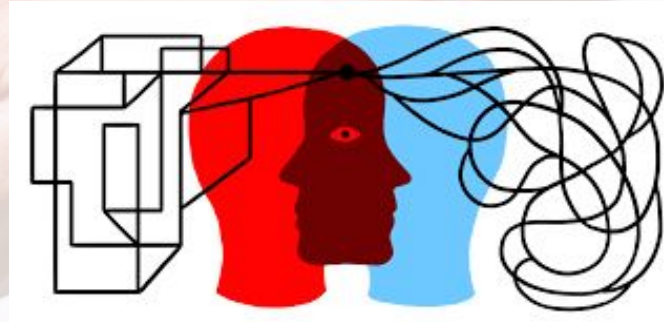
Dementia: Subtypes

- Alzheimer disease (60-80%)
- Vascular (strokes)
- Frontotemporal ("dirty old man/woman")
- Parkinson disease (dementia is late feature)
- Huntington disease (motor > cognitive)
- Lewy body (psychiatric features)
- Wernicke-Korsakoff (alcohol)
- Normal pressure hydrocephalus (early=reversible; late=irreversible)
- Creutzfeldt-Jakob ("mad cow")
- Traumatic ("punch drunk", sports)
- Human immunodeficiency virus (HIV, dementia is late feature)
- Mixed (Alzheimer + vascular = common)



Cognitive: Intellectual & Developmental Disability

- Broad category of disorders, including:
 - **Autism spectrum disorders**
 - Acquired disorders
 - Kernicterus, TBI
 - **Congenital disorders**
 - Cerebral palsy, Fetal alcohol syndrome
 - **Genetic & intellectual disorders**
 - Down Syndrome, Fragile X disorder, trisomies
 - Attention & sensory processing disorders
 - Vision & hearing disorders
 - Musculoskeletal disorders
 - Muscular dystrophy
 - Learning disorders
 - Dyslexia



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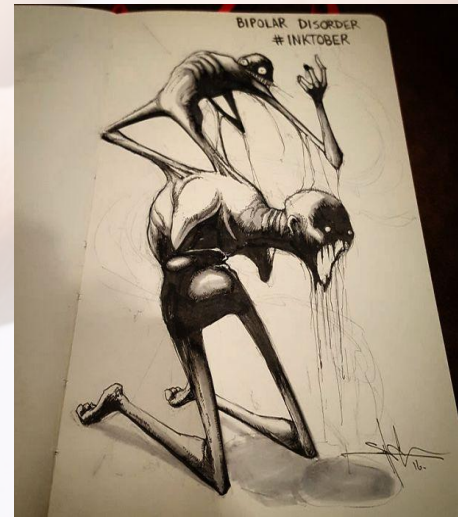
Psychiatric: Schizophrenia

- Chronic/recurrent psychosis & functional impairment
- Characterized by “positive” (additive) & “negative” (deficit) symptoms
 - Hallucinations (+)
 - Delusions (+)
 - Paranoia (+)
 - Disorganized (+) and/or impoverished (-) speech
 - Impaired attention, memory, executive brain functions (-)
 - Catatonia (-)
- Can be extremely disabling & hard to manage
- Societal economic costs are high
- Stigma: self & others
 - **5% commit suicide**; 10% of all suicides in people with schizophrenia

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Psychiatric: Bipolar Disorder

- Characterized by a mix of depressive episodes, hypomania, and sometimes manic episodes
 - Delusions & psychosis possible
 - Rapid cycling: 4 episodes in 12 months
- 10-15% die by suicide
- Occurs across lifespan, pediatric geriatric
 - 25% of bipolar disorder in adults age >60 years
 - 40-50% of older adults with bipolar disorder have cognitive impairments
 - Associated with dementia (\uparrow 2x)



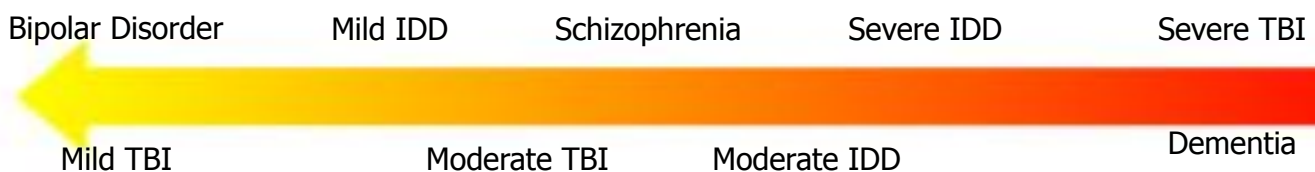
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Overall Prognoses:

Relative likelihood of capacity restoration, with improvement such that guardianship is no longer need:

More Likely

Less Likely



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Capacity Determination

- Limited to physicians [MD, DO, MBBS], licensed psychologists.
 - Newly, nurse practitioners with physician oversight, also.
 - This is for official guardianship documentation only.
- Not just Geriatricians, Psychiatrists, Neurologists, PCPs!
- However, most physicians rarely determine capacity.
 - Time
 - Training
 - For reference: In the last 6 years, 525+ capacity assessments performed
 - Compensation

Capacity Assessment

- Five areas of function interview
- Physical examination
- Cognitive testing
- Additional questions
- Collaterals

Five Areas of Function Interview

- Food
- Clothing
- Shelter
- Physical Health
- Finances

Food

- **Ask:**
 - How do you get food? What do you eat? How do you prepare food? Do you have enough food? Have you lost or gained weight recently? Can you clean your own kitchen and dishes?
- **Observe:**
 - Expiration dates, spoiled foods, limited variety of food, overflowing trash cans, dirty kitchen, insects or rodents, inadequate quantity of food, hoarding or significant clutter, etc.

Clothing

- **Ask:**

- Are your clothes in good shape? Do your clothes fit well? Are your clothes warm enough? Do you need more clothes? Can you afford more clothes? Do you need help dressing? How do you wash and dry your clothes? How often do you do your laundry?

- **Observe:**

- Overly worn out clothes, dirty or soiled clothes, weather inappropriate clothes, failure to change clothes regularly, piles of unwashed clothes, broken washer and dryer appliances, etc.

Shelter

- **Ask:**

- What type of home do you have? Can you afford your home? Who lives with you? Is your neighborhood safe enough? Can you clean your own home? Do you have working utilities? Are your major appliances working? What is broken in your home? Does your home have any internal or external damage?

- **Observe:**

- Hoarding or excessive clutter, unsanitary conditions, run-down appearance, absence of utilities, broken appliances, unrepaired home damage, safety hazards, infestations, inadequate climate control, etc.

Physical Health

- **Ask:**

- How often do you bathe? Do you need help bathing or grooming? Do you have a regular doctor? When did you last see a doctor? Have you been to an ER or hospital recently? How do you manage your medications? Do you have medicolegal paperwork, like a Power of Attorney? Do you have medical insurance? Are you feeling well today?

- **Observe:**

- Signs suggesting acute physical or psychiatric illness, malnutrition and dehydration, pill boxes or pill bottles, gait assistive devices, unwashed or disheveled appearance, etc.

Finances

- **Ask:**

- Do you have a bank account? Who has access to your money and bank account? What income do you receive? Do you have enough money to pay for your basic needs regularly? How do you pay your bills? Do you have any late or outstanding bills currently?

- **Observe:**

- Contradictory reports of adequate funds in the presence of disconnected utilities, inadequate food, or sparse furnishings, difficulty discussing details of finances and bill pay, mentions of financial support of new friends or romantic partners especially those who are much younger, etc.

Capacity Assessment

- Five areas of function interview
- Physical examination
- Cognitive testing
- Additional questions
- Collaterals

Physical Examination

- Signs of acute physical illness
 - Rapid / heavy breathing, leg swelling, skin rashes / discoloration, musculoskeletal deformities, slurring, facial asymmetry, muscle or temporal wasting, confusion
- Signs of acute psychiatric illness
 - Hallucinations, delusions, mood, affect, speech and thought content, agitation or somnolence, altered insight / judgement, confusion
- Signs of delirium
 - Acute onset or fluctuating course of mental status changes with inattention and disorganized thinking and / or altered consciousness
- Signs of intoxication
 - Pupil changes, slurred speech, disinhibition, openly drinking alcohol, falling

Capacity Assessment

- Five areas of function interview
- Physical examination
- Cognitive testing
- Additional questions
- Collaterals

Cognitive Testing

- Saint Louis University Mental Status (SLUMS)
- CLOX 1 and CLOX 2
- Trail Making Part A and Part B
- Geriatric Depression Scale (GDS)

SLUMS



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CLOX



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Trail Making Part A



Trail Making Part B



OF COURSE THE TESTS ARE NONSENSE, BUT WE'RE WORKING ON THE BASIS THAT ANYONE WHO CAN BE BOTHERED TO COMPLETE ALL 148 OF THEM *MUST* BE HIGHLY MOTIVATED!

IS THIS PICTURE OF AN ELEPHANT MORE OR LESS LIKE A JAR OF MARMALADE?

psychometric testing inc.



Capacity Assessment

- Five areas of function interview
- Physical examination
- Cognitive testing
- Mood testing & additional questions
- Collaterals

GDS



Additional Questions



- Suicidal and homicidal ideations
- Delusions and hallucinations
- Mistreatment
- Delirium
- Idiomatic expression interpretation

Capacity Assessment

- Five areas of function interview
- Physical examination
- Cognitive testing
- Additional questions
- Collaterals

Collaterals

- Adult Protective Services specialists
- Adult Protective Services narratives
- Medical records
- Facility records
- Photography
- Videography
- Law enforcement reports
- Educational records
- Testing records
- Family, friends, neighbors, known contacts

Determination

- Results from capacity assessment will be compiled and taken in totality
 - Poor cognitive tests alone, even in dementia range, don't make incapacity alone
 - Dementia is not the same as incapacity
- Consideration of next steps for safety
 - Emergency removal
 - Guardianship

Emergency Removal

- Only when an adult “is suffering from abuse, neglect or exploitation to a degree that it presents a threat to life or physical safety”.
- Must be able to convincingly convey risk to reviewing judge on Emergency Order For Protective Services (also called Exhibit B)
- Removal from home environment to safe new location results

Guardianship

- Lengthy process by which a judge evaluates medical claim of incapacity to determine if incompetency present
- If found to need guardianship, new ward is assigned an unrelated guardian or an individual known to the ward (e.g., family, friend) assumes responsibility.
- This process alone has many associated costs (legal fees, guardian bonding fees, probate court for estates / assets, etc.)

All done!

...?



Guiding Principles

- Supported decision-making
- Person-centered decision-making
- Trauma-informed care & decision-making
- Respect for existing goals, beliefs & values

Supported Decision-Making

- ACLU definition

"Tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices ... trusted advisors, such as friends, family members, or professionals ... [who] agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions."

Supported Decision-Making

- Not one size fits all
- Includes:
 - Plain language
 - Visual/audio alternatives
 - Extra time
 - Pros/cons lists
 - Role-playing activities
 - Support person(s) involved in activities
 - And much much more!
 - Key: creativity, kindness



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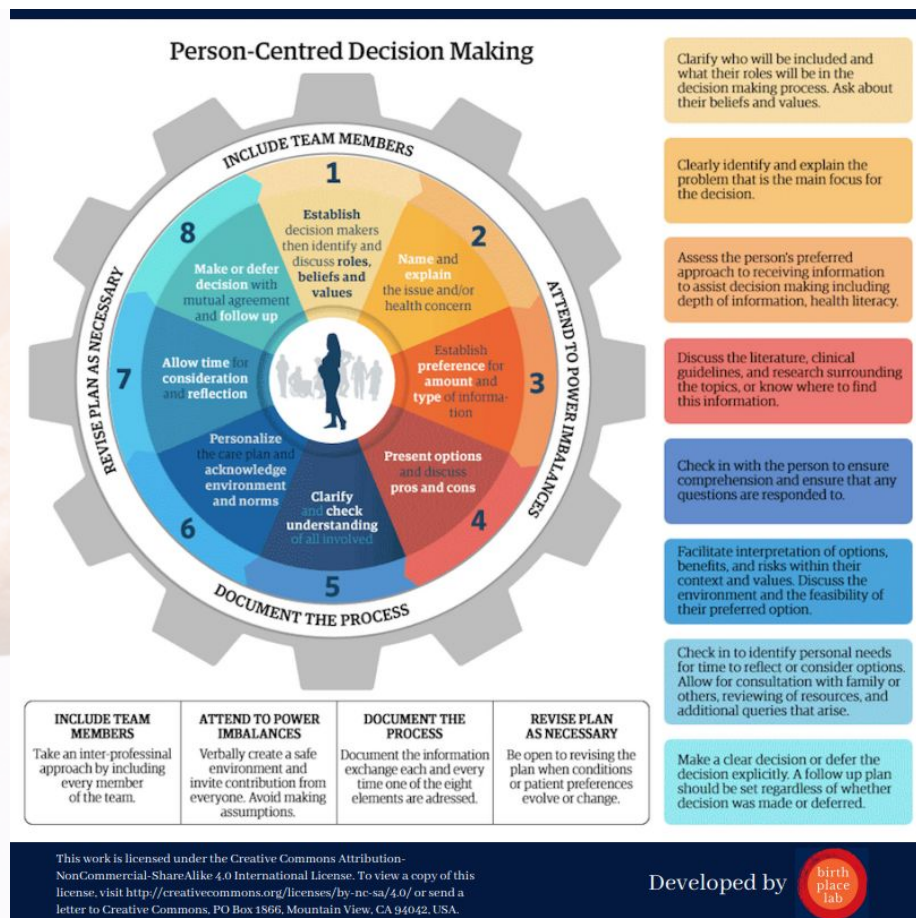
Supported Decision-Making

- FORMALLY recognized option in Texas with FORMAL documentation
- Exists to “help doctors, bankers, lawyers, and other third parties to feel confident in accepting the decision of the person with a disability without fearing lawsuits or malpractice claims.” -ACLU
- Not a **substitute** decision-maker (e.g., POA), but a **support**
- Not a **contract**, but an **authorization**

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Person-Centered Decision-Making

- Individual Program Plan (IPP)
 - Documentation of individual's personal & family preferences
- Guides future planning
 - Especially in progressive disabilities where incapacity for independent decision-making is expected to worsen over time



Trauma-Informed Care & Decision-Making

THE PRINCIPLES OF TRAUMA-INFORMED CARE:



Safety



Transparency



Peer Support



Collaboration



Empowerment



Humility & Responsiveness

- An approach to care that “acknowledges that ... care teams need to have a complete picture of a patient’s life situation – past and present – in order to provide effective ... care services with a healing orientation.”

Trauma-Informed Care & Decision-Making

Goals:

- Recognize widespread impact of trauma & understand recovery paths
- Recognize signs & symptoms of trauma
- Integrate knowledge about trauma into policies, procedures, practices
- **Actively avoid re-traumatization**

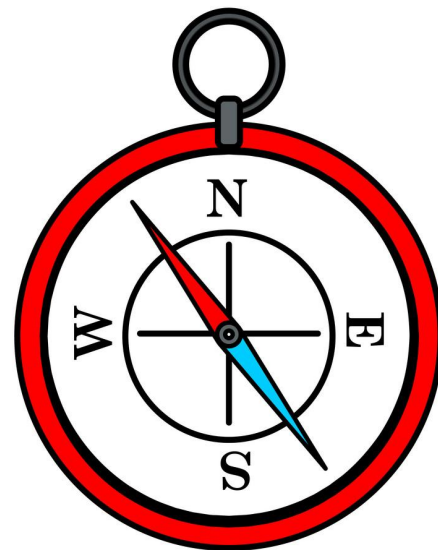
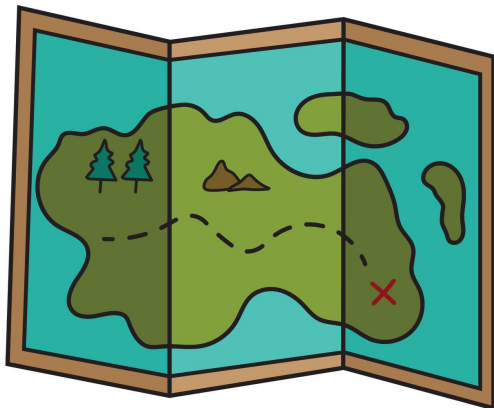
How to Support Someone Who Has Experienced Trauma



Respect for Goals, Beliefs & Values

- Integration of the immediate, short, and long-term
- Personal, family, community, nationality, racial, ethical, moral, legal, religious, spiritual, emotional, physical, cognitive, psychological, safety, educational, and much more!
- A way of guiding decision-making to ensure highest quality of life

Which One Are You?





Summary

- Neurologic (stroke, traumatic brain injury), Cognitive (dementias, intellectual and developmental disorders), and Psychiatric (schizophrenia, bipolar) conditions are the most common causes of incapacity in adults
- Interview, examination, cognitive & mood testing, use of collateral sources are recommended for thorough capacity assessment
- In addition to guardianship and emergency removal, less restrictive options such as supported decision-making, person-centered decision-making, trauma informed care, and respect for goals, beliefs, and values can support individuals with incapacity
- In select cases, capacity restoration may be appropriate, depending on the original underlying etiology of incapacity



**Julia.A.Hiner
@uth.tmc.edu**



302.803.2320



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THANK YOU!



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