Assessing Independent Living Capacity in Older Adults

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Self Neglect: Balancing Autonomy and Risk
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Disclosures

- Contributed to a chapter on Elder Self-Neglect and IL Capacity assessment
- Opinions shared in this talk are not the opinions of the US Government or the US Department of Veteran Affairs

Elder Self-Neglect (ESN)

- Complex, multifactorial syndrome
- Not a clinical diagnosis (not in DSM-5)
- Lacks a unified definition
  - Defined by National Center for Elder Abuse (NCEA) as: *when a person neglects their own safety in a way that leads to illness or injury*
  - Generally manifests as refusal or failure to provide adequate water, food, clothing shelter, personal hygiene, medication and safety precautions (NCEA, 2019)
- Most frequently form of elder abuse reported to adult protective service (APS) agencies
- Risk factors are demographic, social and physiologic in nature
- Often raise questions about an individual's ability to remain living independently (i.e., independent living capacity)

Objectives

- Define capacity---> then independent living capacity
- Understand when to consider a capacity for independent living evaluation
- Know the essential elements of an IL capacity eval
- Understand who can help in the evaluation
- Appreciate community resources that can be accessed to help someone who lacks capacity for IL
- Know what the next steps are when someone is found to lack capacity

What is Capacity?

- Definition of capacity depends on the type of abilities being questioned (function-specific)
  - Health Care Management/Medical Decision-Making
  - Independent Living/Refusal of Placement
  - Finance Management
  - Testamentary
- Not the same as competency

What is Capacity?

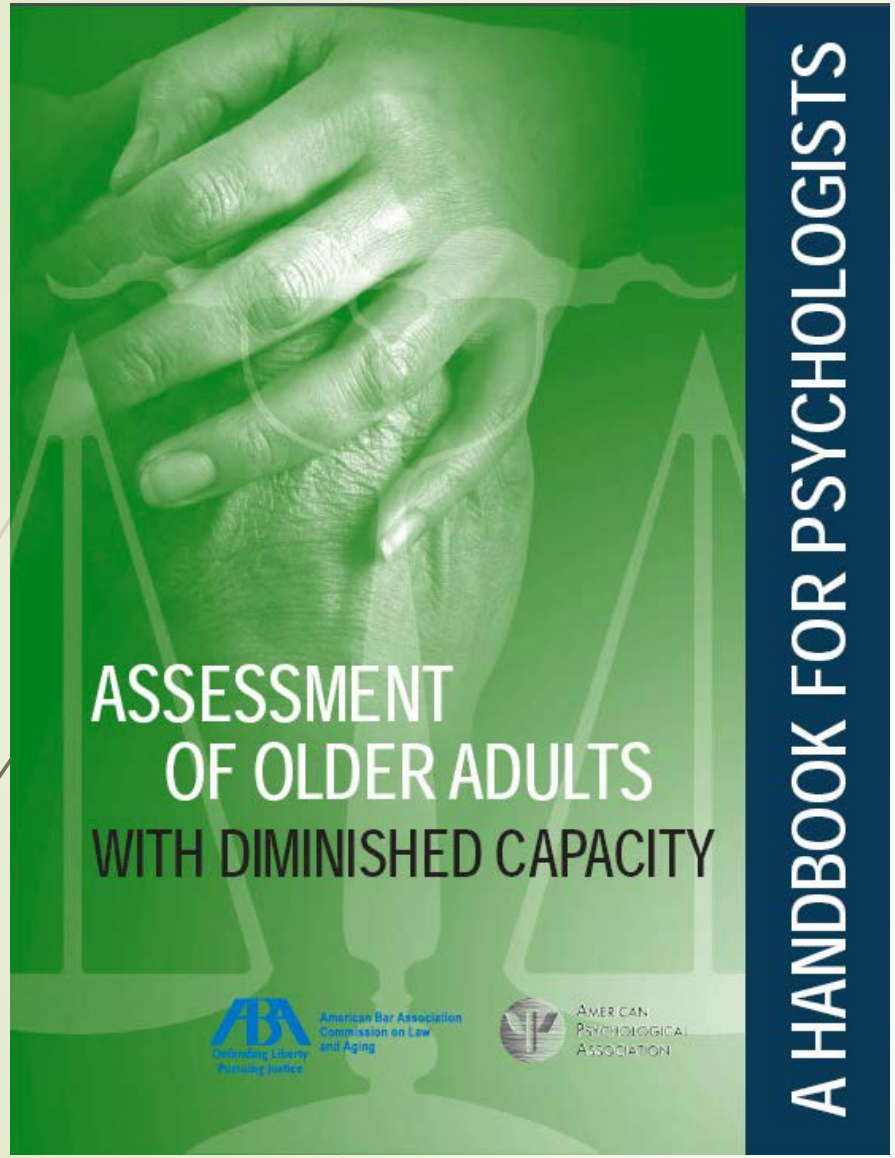
- Threshold is higher or lower depending on the risk of the outcome (e.g., life threatening medical procedure vs. appointing a health care proxy)

- Viewed on a continuum(has capacity--diminished capacity-- lacks capacity)

- Degrees of intervention (e.g., strategies to enhance capacity, utilize supports, designate a surrogate decision-maker)

- May fluctuate over time

Gold Standard for Assessing Capacity in Older Adults



https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

What is Independent Living (IL)?

https://lao.ca.gov/Publications/Report/3509

When to Consider an IL Capacity Evaluation

When an individual's ability to function safely in their own home becomes a concern (warning signs)

Identify strengths and weaknesses to help inform appropriate intervention

IL capacity eval referral questions are often two-fold

- **Does the individual have capacity to remain in the home?**
- **Are there any additional services/interventions to enhance capacity and remain in the home, that the person is willing to except?**

Warning Signs

- Decline in ADLs/IADLs
- Difficulties with chronic illness self-management, including medications
- Not keeping appointments
- Difficulty managing finances, paying bills *(e.g., utilities shut off, housing insecurity)*
- Inability to access emergency services *(e.g., 911, use emergency alert device)*
- Decreased safety awareness *(e.g., leaving appliances on, unlocked doors, potential for exploitation from others)*
- Failure to thrive *(e.g., poor oral intake, weight loss, reduced activity and interest, decline in ADLs)*

Risk Factors for Diminished IL Capacity

- Living alone
- Isolation
- Frailty
- Psychiatric conditions
- Cognitive impairment
- History of self-neglect
- Lack of supports (family, community, medical, etc.)

When to consider an evaluation for independent living capacity

"Evaluations for independent living capacity need to determine if an individual is a significant danger to her or himself due to limited functional abilities, or due to cognitive or psychiatric disturbances, and also cannot accept or appropriately use assistance that would allow him or her to live independently"

(ABA-APA, 2008)

Framework for IL Capacity Evaluation

- 1. Legal standard
- 2. Functional elements
- 3. Medical conditions causing impairment
- 4. Cognitive underpinnings
- 5. Psychiatric and emotional factors
- 6. Values and preferences
- 7. Risk considerations
- 8. Means to enhance capacity
- 9. Clinical judgment

IL Legal Standard

State statutes for incapacity under guardianship vary widely, but many cite one or more of the following:

- The presence of a disabling condition
- A functional element—sometimes defined as the inability to meet essential needs to live independently
- A problem with cognition
- A necessity component—that is that the guardianship is necessary because less restrictive alternatives have failed

(ABA-APA, 2008)

IL Functional Elements

Abilities (Understanding and Application of ADLS and IADLS)

- Personal Care and Hygiene
- Health Care
- Finances
- Home Care
- Community

Knowledge and Judgment

- Insight
- Ability to Accept Help

Functional Assessment

- **Direct Observation**
- **Collateral Informant Interviews**
- **Performance Based Standardized Functional Assessments:**
  - KATZ Index of Independence in ADLs *(any discipline, informant version)*
  - Lawton & Brody IADL scale *(any discipline, informant version)*
  - OTAPS vs KELS *(OT)*
  - Independent Living Scales (ALS), Texas Functional Living Scale (TFLS) (Psychologist)
- **Home visits can be informative**
  - assess home environment, observe ability to perform IADL/ADLs in real-time

Cognitive Screening/Evaluation

- **Various Screening Measures --*Examples:***
  - Mini Mental State Examination (MMSE)(Folstein, 1975)
  - Montreal Cognitive Assessment (MoCA)(Nasreddine, 2005)
  - General Practitioner Assessment of Cognition (CPCOG) (Brodaty, 2002)
- **Executive functioning (EF) is the best predictor of functional ability**
  - MMSE does not assess EF
  - MoCA assesses EF, but can be tricky to accurately eval in someone with a low education
- **May need comprehensive neuropsychological evaluation**
  - Attention
  - Processing Speed
  - Visuospatial Abilities
  - Executive Functioning
  - Language
  - Learning and Memory

Values and Preferences

Values: underlying set of beliefs, concerns, and approaches that guide personal decisions

Preferences: the preferred option of various choices--informed by values

**May change with experience and are influenced heavily by family, social network, religious, spiritual, cultural, and health beliefs*

Psychiatric/Emotional Functioning

Factors that can influence IL Capacity:

- Severe depression → motivation
- Severe anxiety → impaired processing, indecision
- Trauma-Related Disorders → issues with trust, safety
- Hoarding → safety of the environment
- Psychotic Disorders
  - Negative symptoms can affect motivation
  - Cognitive symptoms can affect understanding and ability
  - Both can affect judgment
- Substance use disorders→ inadequate self –care, financial mismanagement

Risks

- *Weight the risks of the individual continuing to live independently without adequate supports and supervision*
- *Are there less restrictive alternatives/interventions that the individual will agree to?*
- *Ethical Issues of Autonomy vs. Protection are often at the heart of this question*

Means to Enhance Capacity for IL

- **Health Care Alternatives**
  - Durable power of attorney
  - Living Will
- **Financial Management Alternatives**
  - Rep Payee/Fiduciary
  - Power of Attorney
- **Personal Care Alternatives**
  - Home Health
  - Case Management
  - MOW
  - Adult Day Care
  - ALF, SNF, group home

https://www.ridlc.org/media/publications/ridlc-guardianship-booklet.pdf

Clinical Judgment

***Clinical* Judgment:** integrate the data and offer a clinical opinion about the patient's capacity for independent living based on the following:

Understanding:	Application:	Judgment:
Does the individual understand day-to-day requirements of taking care of self and home?	Is the individual able to demonstrate the required for living independently, safely?	Does the presence of a cognitive or psychiatric disorder affect the patient's individuals judgment re: self or home care?

Recommendations*:*

-interventions to enhance capacity

-requires a more supervised living arrangement

-recommend designated surrogate decision-maker

-petition for guardianship

Case Example

Mr. F

- 87 yo, married, male, Korean-Era, Air Force, Veteran
- 12 years of formal education
- Retired lace weaver
- Lives with wife in single family home—dilapidated, electricity and plumbing issues
- Married 60+years, only son died tragically in 30's
- Limited family support (wife, nephew and nephew's wife)
- No Advance Directive

PHI

- Osteomyelitis
- Diabetes mellitus
- Chronic kidney disease
- AV block
- H/O Pneumonia
- Hyperlipidemia
- Sensorineural Hearing Loss, Bilateral
- Hypertension
- Major Neurocognitive Disorder, Unspecified, with behavioral distrubance
- Long-standing history of poor self-care, non-adherence to medical recommendations, refuses to attend appointments—often leads to admissions and discharge AMA—risky behaviors

Medications & Supplies

- ASPIRIN (stroke prevention)
- DONEPEZIL (Dementia)
- HYDROCHLOROTHIAZIDE (Fluid and blood pressure control)
- INSULIN (Diabetes)
- METFORMIN (Diabetes)
- VALSARTAN (Blood Pressure)
- ATTENDS BRIEFS
- COMFORT BATH

HPI & Warning Signs

- 2013 Dementia diagnosis, prescribed donepezil
- 2017 Referred for outpatient neuropsychological evaluation and concerns about decision-making capacity due to poor insight felt to be impacting his health care management—no follow through
- Driving on suspended license with evidence of damage to vehicle
- 2017-2019 Multiple reports to Adult Protective Services (APS) for self-neglect—Vet and wife refused intervention
- 2/2019 Vet referred to VA Home-Based Primary Care (HBPC) program
- Ongoing concerns about self neglect (poor hygiene and diabetes self-management, weight loss, risk taking behavior) and aggressive behavior toward wife
- HBPC RN and SW coordinated with APS and community-based providers to offer additional home-based services and home repairs. Couple refused help
- Would not give permission to involve nephew/nephew's wife
- APS requested an IL Capacity Evaluation for further intervention (SNF placement)

IL Capacity Evaluation

- Chart review
- Consultation with RN/NP/SW/APS
- Joint visit with RN/APS
- Clinical Interview
- Cognitive Screening
- Psychiatric
- Practical Judgment Questionnaire –poor judgment and decision-making
- Functional Assessment– ILS, direct observation; collateral data
  - Independent Living Scale (ILS)
    - Managing Home & Transportation
    - Health & Safety
    - Social Adjustment
- Values/Preferences Assessment

Results

- **Functional Assessment**: *dependent for ADLs and IADLs*
- **Medical Conditions Causing Impairment**: *Dementia, Poorly controlled DM*
- **Cognitive Assessment**: *MoCA Blind = 9/22 (below cutoff of 18)*
- **Psychiatric/Emotional Functioning**: *no prior history, denied symptoms on ROS, negative screens*
- **Values and Preferences**: *independence, privacy, be with his wife*
- **Risks**: *self-neglect, malnourishment, med non-adherence, driving, poor judgment*
- **Means to Enhancing Capacity**: *No AD, h/o refusing home-based services, refusing ALF*
- **Clinical Judgment**: *Lacks capacity*

Results & Interventions

- **Results:** Significant impairments in cognition, IADLs and ADLs
- **Impression**: Major Neurocognitive Disorder, Unspecified. Lacks capacity for independent living.
- **Recommendation**:
  - Designate a surrogate decision-maker--? Guardianship
  - Consider Adult Day Health program
  - Supervised, supportive living (ALF, etc.)
- **Interventions (Alternatives to Guardianship)**:
  - Education for wife
  - HBPC/APS/CAP collaboratively work with wife to engage her in accepting assistance with home repairs, decluttering, home health services, MOW, ADH, etc. for 30 day trial period

Outcome

Vet and wife continued to refuse assistance

Least restrictive alternatives were unsuccessful

- Joint visit with APS-- involuntary transfer to ER for evaluation
- Vet was medically admitted to medicine for metabolic abnormalities
- During admission, a medical hold placed due to Vet's lack of capacity for medical decision-making and ? wife's ability to serve as substitute decision maker
- Guardianship petition initiated

Who can address/assess IL capacity issues in at-risk older adults ?

- **Medical Conditions Causing Impairment** (MD, APRN, RN)
- **Functional Assessment** (RN, Rehab Specialists, Case Manager, SW, Psychologist)
- **Cognitive Screening** (Case Manager, SW, RN, APRN, Psychologist, MD)
- **Comprehensive Neuropsychological Evaluation** (Psychologist)
- **Psychiatric/Emotional Assessment** (SW, Psychologist, ARPN, MD)
- **Values and Preferences** (all disciplines, family, caregivers)
- **Risks** (all disciplines)
- **Means to Enhancing Capacity** (all disciplines)
- **Clinical Judgment/Determination of Capacity** (Psychologist, APRN, MD)
- **Legal Determination of Competence/Guardianship** (Judge)

Thank you!

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Questions?

References

1. American Bar Association and American Psychological Association Assessment of Capacity in Older Adults Project Working Group. (2008). Assessment of older adults with diminished capacity: A handbook for psychologists. Washington, DC: American Bar Association and American Psychological Association.
2. Feng, Michelle C,. Murphy, Margaret R., & Mlinac, Michelle. (2017). Independent Living Capacity Evaluation in Home-Based Primary Care: Considerations and Outcomes of a Quality Improvement Project, *Clinical Gerontologist*, 40 (1), 51-62. doi:10.1080/07317115.2016.1210272. PMID: 28111494.
3. Lai, J.M. and Karlawish,K. (2007). Assessing the Capacity to Make Everyday Decisions: A guide for Clinicians and an Agenda for Future Research, *American Journal of Geriatric Psychiatry*; 15, 101-111. DOI:10.1097/01.JGP.0000239246.10056.2e.
4. Moye, J., Wood, S., Edelstein, B., Armesto, J.C., Bower, E.H., Harrison, J.A., & Wood, E. (2007). Clinical evidence in guardianship of older adults is inadequate: findings from a tri-state study. *Gerontologist* 47, 604–612.. DOI: 10.1093/geront/47.5.604
5. Moye, J. et al. (2007). A conceptual Model and Assessment Template for Capacity Evaluation in Adult Guardianship *Gerontologist*, 47, (5) 591-603. https://doi.org/10.1093/geront/47.5.591.
6. Moynihan, G., O'Reilly, K., O'Connor, J., Kennedy, H.G. (2018). An evaluation of functional mental capacity in forensic mental health practice: the Dundrum capacity ladders validation study. *BMC Psychiatry, 18*(1):78 . doi: 10.1186/s12888-018-1658-2.
7. Naik, A.D., Lai, J.M., Kunik, M.E., Dyer, C.B. (2008). Assessing capacity in suspected cases of self-neglect. *Geriatrics* 63, 24–31.
8. National Center for Elder Abuse (2019). Types of abuse. Alhambra, CA: NCEA. Retrieved from https://ncea.acl.gov/Suspect-Abuse/Abuse-Types.aspx#self
9. Skelton, R., et al. (2010). Determining if an older adult can make and execute decisions to live safely at home: A capacity assessment and intervention model. *Archives of Gerontology and Geriatrics,* 50, 300-305. doi: 10.1016/j.archger.2009.04.016.