APS TARC
Adult Protective Services Technical Assistance Resource Center
enhancing effectiveness of APS programs

Understanding Decisional Capacities of Older Adults

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Disclaimer

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About the APS TARC

The mission of the APS TARC is to enhance the effectiveness of state APS programs by:

- Supporting federal, state, and local partners’ use of data and analytics,
- Applying research and evaluation to practice, and
- Encouraging the use of innovative practices and strategies.

Peer to Peer Calls

Have you ever wished that you could tap into the expertise of other APS workers, supervisors or state administrators who are struggling with the same issues and concerns that you deal with daily? The APS TARC provides Peer to Peer calls for workers, supervisors and managers/state administrators.

- **Workers' Call:** The 2nd Wednesday of each month
- **Supervisors' Call:** The 3rd Wednesday of each month
- **Administrators'/Managers' Call:** The 4th Wednesday of each month

Register via the link sent out at the end of each month by the APS TARC or email us in order to receive the registration link!

APS & COVID-19

https://apstarc.acl.gov/COVID

- APS Formula Grant Info from ACL
- Resource Information
- Report **Adult Protective Services Study on the Impact of COVID-19**

Housekeeping

- Handouts/Slides are available for download in the "Handouts" section of your webinar control panel. You may download them at any time.
- Please use your computer speakers to access audio for this webinar. Please make sure the speaker volume is adjusted to your desired volume.
- If you experience audio problems due to internet connection speeds or hardware issues, we recommend exiting the webinar and re-entering.

Housekeeping

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- This webinar is being recorded and all registrants will receive an email when the recording is made available on the APS TARC website.
- All attendees will receive an automatically generated email approximately 24 hours after the webinar ends with a link to a certificate of attendance.

Quick Attendee Poll

Which of the following do you identify the most with?

- Adult Protective Services Professional
- Other Social Services Professional
- Medical Professional
- Legal Professional
- Other

Our Speaker

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Intent of this training

- To share
  - An overview of aging and decision-making capacity
  - A conceptual framework psychologists/neuropsychologists use for assessing capacity
  - Age-related disorders impacting decisional abilities
- To highlight
  - The importance of person-centered holistic assessment and recommendations that emphasize the “least restrictive alternative”
  - The delicate balance between competing ethical principles of autonomy and beneficence
  - Cultural considerations in assessing decision-making capacity
- To explore
  - Ways that psychologists and APS can partner for a better referral process and utilization of expertise (on both ends!)

Capacity Assessments and APS

Complex scenario:

- Mr. Richards was a 51-year old, never-married African American gentleman who was living with his 91-year old father for the past 25 years. APS opened a case following a report by a Veterans Administration (VA) social worker who was assisting the client's father and who had visited the home for an assessment.
- The VA social worker reported poor living conditions and had concerns for Mr. Richards and his father, who were both considered at-risk adults. Mr. Richards' father was the client's rep-payee due to Mr. Richards having a diagnosis of Intellectual/Development Disability from prior testing and a history of mental illness resulting in two documented psychiatric hospitalizations within the past year.
- Mr. Richards' father was being assessed by the VA for placement to a higher level of care (due to dementia and medical comorbidities). Concerns were expressed about Mr. Richards' ability to live independently as he stated his preference was to find an apartment following his father's relocation. Additional concerns included his father's ability to continue managing Mr. Richards' finances in his role as rep-payee.

Whew!
Where to begin?

- Potentially, two referrals for evaluation:
  - Son: Does he have capacity to live independently and make decisions around his living situation?
  - Father: Does he have capacity to make independent decisions around his health care, current living situation, and is he able to continue to manage his son's financial affairs?
- Additional considerations:
  - Are any family members involved to provide supportive decision-making? Or will either individual require a surrogate decision-maker?
  - What is the least restrictive living situation for both individuals given each of their cognitive/psychiatric strengths and limitations?

Competency vs. Capacity

- Competence: Legal term used for a person who is mentally incapable of making autonomous decisions on his/her behalf.
- Courts in most states are favoring the term “capacity”
  - **Clinical Capacity**: as designated in a medical/clinical setting
    - A clinical judgment as to whether an individual has the ability to successfully carry out a specific task or make a specific decision.
    - Clinical findings of incapacity does not change a person’s legal status.
  - **Legal Capacity**: as designated by a court
    - Refers to the specific ability or abilities under law sufficient to carry out a specific action.
    - Courts decide: Does this person have capacity to execute a will or make a treatment decision?
    - Courts’ decision of incapacity does alter a person’s legal status.

A Shift in the Concept

- Probate law viewed capacity as an absolute and global concept
- Now has shifted towards task-or decision-specific standard
- What does that mean?
  - Person can have capacity in one area and not in another

- Evaluations have evolved to include neurocognitive, psychological, and functional assessments using a spectrum of domain-specific measures.

Types of Capacity (ABA/APA, 2008)

- Capacity to consent to **medical care**
- **Testamentary** capacity: to make a will
- **Donative** capacity: to make a gift
- **Financial** capacity: business transactions, managing personal finances.
- Capacity to execute a durable power of attorney (**DPA)** for finances or healthcare
- Capacity to consent to **sexual relations**
- Capacity to **drive**
- Capacity to participate in **mediation**

Definition of an “Incapacitated Person”

“… someone who is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with ***appropriate technological assistance***.”

(Uniform Guardianship and Protective Proceedings Act, National Conference of Commissioners on Uniform State Laws, 1997)

The 2017 Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act– *Long name, Big changes*

Old Approach

- ”Ward” and ”Incapacitated Person”
- Individuals were typically left out of the process – uninformed of their rights and without careful assessment of values and preferences

New Approach

- “Adult subject to guardianship”
- Individual subject to conservatorship”
- Individuals provided with plain-language explanation of their rights.
- Person-centered plans created by guardians and monitored by the courts when possible.

Aging Demographics: What the numbers tell us

- By 2030, 71 million adults over age 65
- 65+ accounts for ~20% of the U.S. population (Centers for Disease Control and Prevention & The Merck Company Foundation, 2007)
- Normal aging is associated with cognitive decline
- Each person has a culmination of strengths and deficits that contribute collectively to functional abilities.
- Normal cognitive aging with other factors can place older adults at risk for impaired capacity and vulnerability to exploitation. (National Center on Elder Abuse, 2005)
  - Example: Sensory impairment, isolation, mood disturbance, emotional dependency.

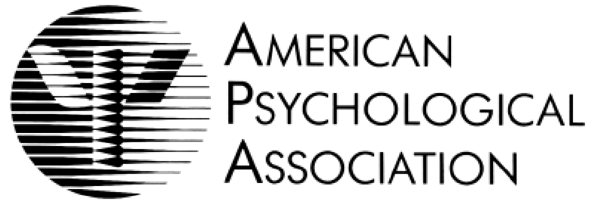
Cognitive Impairment

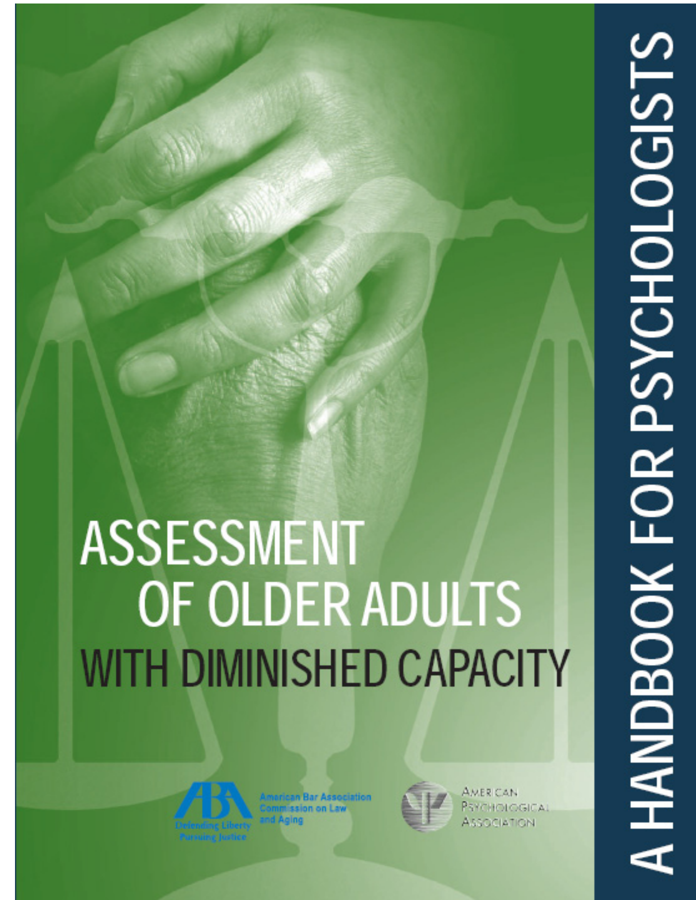
- Risk of cognitive impairment increases greatly with age.
- By 2030, 7.7 million adults in the U.S. over the age 65 will have dementia due to Alzheimer's disease (Alzheimer's Association; www.alz.org/alzheimers-dementia/facts-figures);
- By 2050, over 15 million affected;
- Dementia places individuals at risk for difficulties with decision-making;
- Increasing prevalence of dementia = rise in capacity assessments.

Societal Influences

- A massive transfer of wealth from WWII to Baby Boomer generation (Havens & Schervish, 2003)
- Blended families living apart, often resulting in increasing family conflicts over a loved one's medical care and financial disposition.
- Rise in contested wills and guardianships in probate courts.
- High prevalence of elder abuse, exploitation, and undue influence by strangers, friends, family members, and even professionals.

2008 APA/ABA Commission on Law and Aging





Elements of Consent Capacity

- **Expressing a choice:** Ability to express a choice over time.
- **Understanding:** A person can consent to or refuse medical treatment if he/she is able to understand:
  - **The nature and seriousness of the illness, disorder, or defect;**
  - **The nature of the recommended medical treatment;**
  - **The probable degree and duration of benefits and risks of any intervention, including consequences of lack of treatment;**
- **Appreciation (insight):** Ability to relate treatment information to one's personal situation, including hypothetical future medical situations, and infer the possible benefits of treatment.
- **Reasoning:** Ability to state rational explanations or process information in a logical manner. Should be consistent with the person's values (Applebaum & Roth, 1981; Moye et al., 2008)

Factors Impacting Decisional Capacity

- Cognitive deficits can occur secondary to age-related medical diseases.
  - 2004 Medical Expenditures Panel Survey
  - 49% of all US adults have at least 1 chronic medical condition; 26% have 2 or more.
  - 72% of US adults over the age of 65 have 2 or more conditions.

- Factors leading to diminished mental capacity:
  - Electrolyte imbalance
  - Dehydration
  - Sleep disturbance (insomnia/hypersomnia)
  - Medication effects
  - Malnutrition
  - Vitamin deficiencies
  - Fatigue, pain, inflammatory processes

Characteristics of Capacity: Psychiatric or Emotional Factors

- Evaluate psychiatric and emotional disturbances.
- Persons with psychotic disorders and severe mental illness (SMI) may still be able to process information.
- Psychiatric disorders may improve with time and treatment.
  - Recommend timeframe for re-testing.
- Establishing the impact of SMI in judgment is challenging
- Psychiatric comorbidities are common in persons with dementia and can negatively affect decision-making capacity.

Characteristics of Capacity: Values and Preferences

- **Values:** beliefs, concerns, approaches.
- **Preferences:** preferred option informed by values
  - Are these consistent with previously held values/preferences?
  - Cognitive impairment does not imply inability to state one's values.
  - Consistency between current choices and long-standing values may indicate capacity.
    - Caveat: ***Values do change.***
  - All persons are entitled to his or her own values.

Cultural Considerations

- Older adult U.S. population is more racially and ethnically diverse than ever before.
- Cultural differences within the older adult population must be considered in the context of unique historical, economic, and social factors.
- Western (individualistic) culture emphasizes autonomy; Eastern (collectivist) culture emphasizes collective decision-making.
- Some cultures may have hesitance or mistrust in medical, mental health, and social services professions that can impact levels of engagement.
- Language barriers.

Characteristics of Capacity: Risk of Harm & Supervision Required

- What is the risk of the individual and his or her current situation?
- Consider the individual's social context:
  - Increased social support can decrease risk.
  - Lack of social support can increase risk.
- Assessment recommendations must:
  - Match the risk of harm and level of supervision required.
  - All recommendations should offer least restrictive options.

Example

- Adult Protection Services referral
- 65-yr old Hispanic male, right-handed, lives alone in same apartment for 8-9 years.
- Client has a history of falls, chronic back pain from a motor vehicle accident (MVA) in 1999, and depressive symptoms related to familial strain and loss.
- Referral question: evaluate current level of cognitive and psychological functioning, and offer opinion on capacity to manage finances.

Tests Administered

- The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)
- Test of verbal fluency (FAS-A)
- Trails A & B
- Texas Functional Living Scale (TFLS)
- Geriatric Depression Scale-Short Form (GDS-15)
- Short Anxiety Screen Test (SAST)

Medications

- Zolpidem tartrate 10mg
- Levothyroxine 150mg
- Mirtazapine 7.5mg BID
- Trazadone 50mg
- Topiramate 100mg BID
- Prednisone 10mg
- Morphine 100mg 5x/day
- Imatrex 100mg
- Diazepam 10mg PRN

Substance and Tobacco Use/ Psychiatric History

- Life-long tobacco use; current use, 1-pack per day.
- No problems with alcohol abuse or dependency.
- No prior history or current use of illegal substances.
- No prior psychiatric diagnoses or treatment history.
- Weight loss = 58 lbs in 6 months
- Poor sleep, fatigue due to interrupted sleep patters
- Denied current or history of suicidal or homicidal ideations; no history of suicidal attempts.

Behavioral observations

- Home and hygiene care is good;
- Pt's affect was markedly labile during the evaluation, e.g., crying uncontrollably, intense anger regarding errors made on testing, and laughing/joking in the presence of a friend.
- Female Friend = 30+ years his junior shows up to evaluation unannounced. She is unemployed, has three young children, and history of domestic violence and legal problems. Expresses wish to become his guardian.

Results

- Cognitive impairments ranged from mild to severe in domains of attention, processing speed, verbal memory, language, and executive functioning. Oriented to day of week, place, and city but NOT date, month, or year.
- English was second language, which could have impacted performance on the language task.
- Performed poorly on tasks of money management and unable to follow a four-step command.
- Clinical symptoms of depression and anxiety which can impact processing speed, attention, and recall.
- Other contributors: possible closed-head injury, polypharmacy, and untreated psych symptoms.
- He was vulnerable to harm and/or exploitation.

Conclusion

- “It is my opinion the patient lacks capacity to effectively manage his financial affairs and would benefit from the establishment of a power of attorney or surrogate decision-maker to assist with these matters.”

- “Technological assistance such as pharmacological and non-pharmacological treatments for untreated mental health disorders could enhance his cognitive functioning.”

- “Given the multitude of contributing factors that impact cognitive functioning, it is unknown to what extent his cognitive impairment is permanent or may be improved if his psychological problems are aggressively treated.”

Supportive Decision-Making (SDM)

- SDM is an alternative to guardianship
- An integrative framework for assessing personal, environmental, and social factors that determine the level of support needed by individuals with varying levels of cognitive impairment.
- Most of us employ SDM in our everyday decisions
  - We consult with family, friends and colleagues in situations where choices are weighed for risks and benefits. *Think about the last time you purchased a car or signed a lease.*

Challenges

- All or nothing decisions for a continuous ability.
- Cognition is a continuous and fluid ability
  - Can fluctuate over time depending on the moment-to-moment health and awareness of the individual.
  - Cognition in older adults is especially impacted by multiple factors:
    - Fatigue
    - Medications
    - Dehydration
    - Metabolic imbalances
    - Infection or disease process
- Persons with capacity may exercise poor judgment (“right to folly”)
  - Making unwise/eccentric decisions by itself does not preclude decision-making capacity.

100
Celebrate

Challenges: Poor agreement

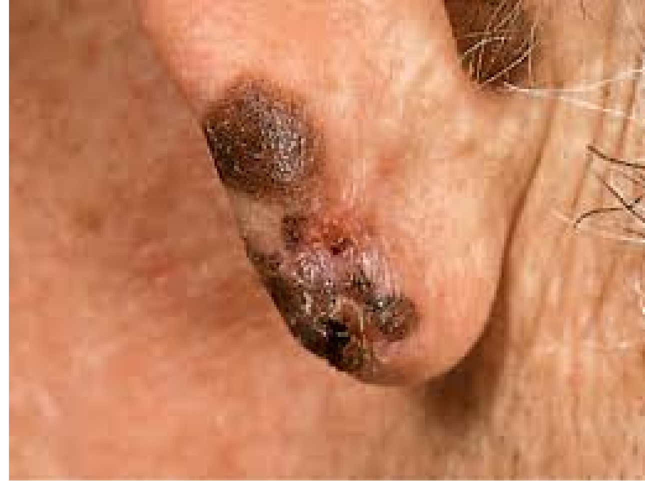
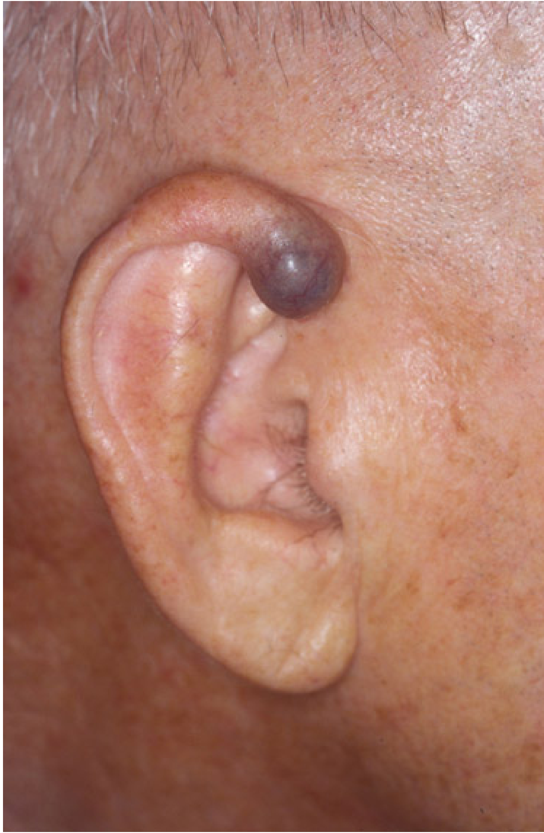
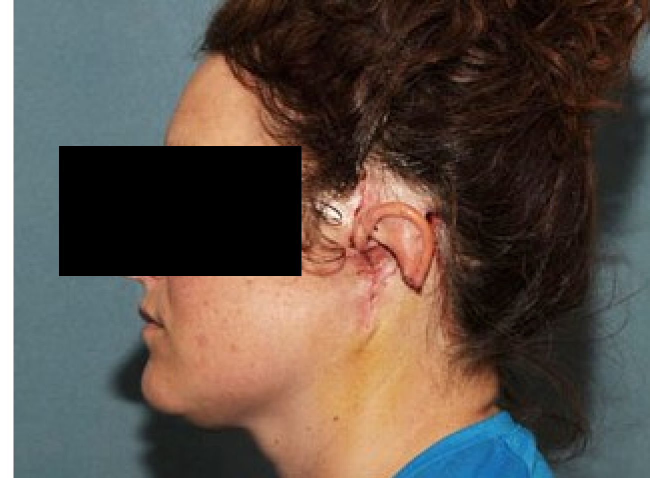
- Poor inter-rater agreement on medical consent capacity.
- Marsen et al. (1997) found only 56% agreement among physicians viewing videotaped capacity evaluations of adults with Alzheimer's disease.
- Why?
  - Different methods used by different evaluators.
  - Complexity is defined by how many aspects of a complex case are evaluated by each assessor.
  - One evaluator weighs more heavily on one piece of evidence for or against capacity than another.
  - Diverse professional and cultural backgrounds.

Maximizing Capacity

- **Treat** the person's physical, emotional, and cognitive problems;
- Present information to **enhance communication**: visual aids, repetition, time of day;
- Test decision-making ability, **NOT solely short-term memory**: present key points in hard-copy format in patient's view so that he/she can refer back as you test his/her understanding of the key points;
- Account for **hearing and visual impairment**: large type print, lighting, glasses/hearing aids, "pocket talker"
- Account for limited English if such is a **second language**;
- **Speak slowly**;
- **Minimize distractions** and background noise.

Case Example

- Patient in his 50s with schizophrenia, living in a group home.
- He has a large cancerous mass (melanoma) hanging from his ear, putting his life at risk.
- Twice he has consented to surgery for this, and then refused when going into surgery.
- No neuropsychologists within 100 miles so he is referred to a clinic from far away.
- Patient explains that he does not want surgery because he will be disfigured.
- He doesn’t seem to understand the life-threatening nature of the melanoma.

Conclusions

- Patient's sister, guardian, did not want to force decision for surgery.
- Patient's psychiatric disorder was being treated and monitored through out-patient services.
- Patient lived in a safe environment.
- Patient could *express a choice, had a reasoning for his decision* which was consistent with his *preferences stated across time and with multiple people*.
- He lacked understanding and appreciation/insight for the severity of his illness and possible implications of refusing treatment.

What happened?

- Determined the patient lacked the capacity to make an informed decision about his medical treatment based on an insane delusion.
- Referred the case for review by a hospital bioethics team.
- Guardian did not contest the patient’s wishes.
- Family and care providers embraced end-of-life care.
- Consider the ethical dilemma.

Common mistakes in capacity reports

- Report misses the capacity question entirely or fails to link the data to the referral question, to the capacity decision;
- Psychologist/Neuropsychologist spends minimal time with the patient; psychometricians vs. neuropsychologist;
- The practical translation of data to the real world – ecological validity;
- The meaning of the data related to the biopsychosocial challenges and strengths.

Referral Process: What, When, and How?

- Embedded in the referral question should be the intended outcome:
  - Is guardianship being pursued?
  - Does the person need to transition to a higher level of care?
  - Is there a safe discharge from the hospital setting to home?

- When sending a referral, be specific about "what" and "when"
  - What abilities are needing to be assessed?
  - When does the evaluation need to happen?

- Sharing records and documentation to aid in the assessment

Enhancing Capacity and Re-assessment

- Maximize the person’s functioning
  - Both during assessment and in recommendations

- In situations where improvement is possible, recommendations for enhancing capacity should be included in the report.
  - Examples: Best methods for communications, visual aids, medication adjustments, counseling, etc.

- Capacity may change over time, particularly with the implementation of treatment or change in living environment.

- A person has the right to challenge a capacity finding or guardianship order.

Q & A

Additional Resources

American Bar Association and American Psychological Association Assessment of Capacity in Older Adults Project Working Group (2008). *Assessments of older adults with diminished capacity: a handbook for psychologists.* Washington, DC: American Bar Association and American Psychological Association.

Uniform Guardianship, Conservatorship, and Other Protective Arrangement Act, 2017. www.uniformlaws.org

Contact Us

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