Facilitating health care decision making for people with intellectual disabilities:

They’re not all alike
Objectives

- Understand the concept of decision making capacity
- Understand that diagnosis or age, alone, do not determine incompetence
- Understand how to facilitate informed decision making in people with ID
5 Maxims of Legal Competence

1. Related to, but not the same as impaired mental states
2. Refers to functional deficits
3. Depends on functional demands
4. Depends on consequences
5. Can change

“The idea that serious mental illness, mental retardation or cognitive impairment renders a person incompetent to make decisions, is obsolete.”

- Grisso & Appelbaum, 1998 Assessing Competence to Consent to Treatment
Decision Making Capacity (DMC)

- Presumed unless proven otherwise
- Not determined by age or diagnosis
- Actual functioning in a specific decision-making context
- Cognitive abilities and affective states

- Grisso & Appelbaum, 1998 *Assessing Competence to Consent to Treatment*
Incompetence

Status of the individual defined by functional deficits (due to mental illness, mental retardation, or other mental condition), judged to be sufficiently great that the person currently cannot meet the demands of a specific decision making situation, weighed in light of its potential consequences.

- Grisso & Appelbaum, 1998 *Assessing Competence to Consent to Treatment*
What is the effect of a person’s mental disorder on actual cognitive functioning?

Functional abilities required for informed consent:
- Understanding of information
- Appreciation of information for self
- Reasoning with information
- Expressing a choice
Person – Task Specific

- Match between abilities and specific DM demand
- No absolute level of ability
- Assessment = investigation of functional abilities and situational DM demands
- Increase functional abilities or decrease DM demands of the situations
- Some people may need a surrogate DM
Capacity is not static
Change in capacities occurs for many reasons and may vary day to day due to:
- Orientation and attention due to febrility
- Bipolar disorder and other mental health conditions
- Medications
- Aging
- Accidents (brain injury)
- Drug and alcohol abuse
Depends on Consequences

- Threshold or degree of ability to make choice
- Depends on resulting degree of harm
- High benefit, low risk
- Low benefit, high risk
- Low–moderate benefit and risk
- Justice requires same threshold as for average person
Voluntariness

People with cognitive limitations are vulnerable.

- Client’s autonomous decision?
- No undue influence? Paternalism?
- Being promised anything if a particular decision is made? E.g. research study?
- Health care provider benefiting in any way? The provider’s research project?
Changes with age

Most predictable generalization:

- Older people are slower
  - Age related slowness is root cause of age related IQ decline (Salthouse, 1991)
  - Active older people w/o brain impairing illness are quicker than those who are sedentary and ill.
Special considerations for people aging with cognitive limitations

- Grief
- Stigma
- Isolation
- Loss of physical and mental functioning
- Depression
- Stigma
Special considerations for people with cognitive limitations

Comprehension
Sufficient time and planned repetitions
Fatigue
Vision, hearing
Ability to pay attention

Assistance/shared decision making
Trusted friends, family, caregivers, health care providers
Assistance in explaining and understanding
Assessment

- Psychopathology/Dx is a threshold not a determination
- Observe or ask about functioning in DM tasks
- Recognize functional task demands
- Consider consequences
- Can the person understand, appreciate significance for self, reason, express choice
Model for obtaining informed consent

- Conversation with patient relatives/friends.
- Set up the environment to facilitate IC for people with possible cognitive limitations.
- Know the limitations of the patent.
- What are the special considerations for THIS patient in particular.
- Provide relevant information according to standards of IC.
- Consider use of a structured interview to assess DMC.

See Applebaum & Grisso.
MacArthur Competence Assessment Tool: MacCAT-T

- Assess patient’s DMC in context of informed consent disclosure.
- Patient’s circumstances are focus of process
- Demands of decision making task are built into the assessment.
- Patient manifests his level of ability given the demands of his specific situation.