NEW YORK STATE OF OPPORTUNITY. | Office for People With Developmental Disabilities

Who Determines Who has the Right to Make End-of-Life Decisions for People with Intellectual and Developmental Disabilities

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Learning Objectives

- Review assessment and task specific nature of capacity to consent
- Describe determination of medical decision-making capacity for individuals with intellectual and developmental disabilities
- Explain requirements under Surrogate Court's Procedure Act 1750-b

Legal Context

- End of life decision making for people with intellectual and developmental disabilities is covered by Surrogate's Court Procedure Act (SCPA) 1750-b
- 1750-b allows for and authorizes certain identified surrogates to participate in end-of-life decision making for people with intellectual and developmental disabilities *in the event that they cannot make this decision themselves and do not have a health care proxy*

What Constitutes a Developmental Disability?

- In New York, Developmental Disability is defined by Mental Hygiene Law 1.03(22) and includes conditions such as intellectual disability (intellectual developmental disorder), autism spectrum disorder, cerebral palsy, Prader-Willi Syndrome, neurological impairment prior to age 22, etc.
- Frequently, people who fall under the requirements of 1750-b will have been found eligible for services through the Office for People With Developmental Disabilities
- It is also possible that a person has been determined to have a developmental disability through the Article 17-A guardianship process or that there are specific situations in which 1750-b applies
- Hospital and Health Care providers may need to consult with their legal counsel regarding applicability of 1750-b to a particular situation

SCPA 1750-b

- Allows for 17-A Guardians, actively involved family members, Willowbrook Consumer Advisory Board representatives (for fully represented members), and the Surrogate Decision Making Committee (SDMC) to make end of life decisions for a person with developmental disabilities in the event that they lack the capacity to make health care decisions and do not have a health care proxy

OPWDD Checklist

- Used when 1750-b is applicable *and* the person with a developmental disability is unable to make a decision for themselves.
- Is available on the OPWDD website:
- https://opwdd.ny.gov/system/files/documents/2020/04/molst-checklist-opwdd-fillable.pdf
- Follows the requirements of 1750-b
- Must be filled out completely and correctly *and* accompany Medical Orders for Life Sustaining Treatment (MOLST) orders
- Checklist must be completed before the physician signs the MOLST

Determining Capacity

- Never assume *incapacity* in people with developmental disabilities
- Even if the information says they have other entities consent for them, make your own decision based on the specifics of the situation

What is Capacity to Consent?

- Capacity is simply defined as the mental ability to understand the nature and consequences of a decision
- Incapacity occurs when there is a mismatch between the *functional abilities* of the person and the demands of the specific situation requiring a decision
- Capacity to make a decision is specific to the decision in question
  - Simple medical decisions – easier to demonstrate capacity
  - Complex medical decisions – greater abilities needed

Capacity Assessment

- Assess four functional abilities:*
  - ability to ***express a choice***
  - ability to ***understand*** information relevant to decision in question
  - ability to ***appreciate*** the significance of that information for one's own situation, especially concerning one's illness and the probable consequences of one's treatment options
  - ability to ***reason*** with relevant information so as to engage in a logical process of weighing treatment options

*Grisso, T. & Appelbaum, P.S. (1998). Assessing competence to consent to treatment: A guide for physicians and other health professionals. New York: Oxford University Press

Capacity Essentials

- Disclosure of information
  - Want to maximize comprehension and understanding of condition
- Assess for understanding
  - Ask the person open ended questions about the information that they have received
  - O.k. to clarify incorrect information and see if they retain correct info

Capacity Essentials

- Ask what their decision is
  - Is the answer/preference clear?
- And how they reached this decision
  - What is the thought process/reasoning that they used to come to this decision?

Communication

- Effectively being able to communicate with the person is essential to making accurate decisions regarding capacity issues
- Communication problems may create a false impression if care is not taken to ensure person has been provided maximal opportunity to respond to information that is provided in a manner that facilitates their understanding

Medical Decision Making

- Need to understand medical condition
- Proposed treatment and alternatives
- Potential benefits and risks involved
- Possible/probable course of disease/condition without intervention

Ability to *Express a Choice*

- This refers simply to the person's ability to clearly express a choice regarding the decision
  - This ability is usually easily met
  - If the person is unable to do this, due to illness or intellectual deficits, they *do not* have capacity
  - Protracted indecisiveness or repeatedly contradicting themselves may also be reasons for not meeting this functional ability

Ability to *Understand*

- This is the demonstrated ability to comprehend the information provided
  - Person must have had sufficient information made available to them about the situation being faced, the decision options and the risks and benefits of each option*
    - * Be sensitive to the person's level of functioning and ability to understand the information being presented
  - Understanding is a basic component of consent. If the individual is not able to demonstrate that they comprehend the information, this ability is not established and the individual does not have capacity

Ability to *Appreciate*

- This refers to the person's ability to appreciate the information *as it applies to their situation*
  - For example, regarding medical decisions, does the person acknowledge that they have the disorder?
  - Do they acknowledge the consequences of the disorder and the potential treatment options for their situation?
- Assessing for patently false beliefs, denial, & delusions *as they relate to the treatment decision*

Ability to *Reason*

- This refers to the person's ability to logically process the information in light of their own preferences when making a decision
- This may be best assessed by asking the person how they made their decision or asking them to "think aloud" while they review the information that led to their decision

Ability to *Reason* (2)

- Emotional stress or anxiety may temporarily interfere with the person's decision making ability
- Mere disagreement with a treating clinician or treatment team is not an adequate basis for determining irrationality—focus is on process, not outcome

Ability to *Reason* (3)

- Not necessarily looking for “perfectly” rational and logical reasoning
- Do want to see that person has taken major factors into account, considered the options and reached a conclusion that is reasonably congruent with their known preferences

Capacity Concurrences

- If person with I/DD is determined to lack capacity for end-of-life decisions (withholding or withdrawing life saving treatment) by attending physician, 1750-b requires that the attending physician "consult" with an OPWDD-connected Licensed Psychologist or Physician

Concurring Clinician Qualifications

- Psychologist or Physician who
  - 1) Employed by OPWDD; or
  - 2) Employed for minimum of 2 years by agency licensed or authorized by OPWDD; or
  - 3) Has been approved by the Commissioner of OPWDD

How does a Clinician get Approved?

- There is a process for approval of clinicians (physicians or licensed psychologists)
- OPWDD regulations (NYCRR 633.10) require specialized training in the provision of services to people with developmental disabilities or at least 3 years experience in the provision of such services
- Process for approval starts with local OPWDD Regional Office

SCPA 1750-b Process

- The actions of the Hospital/Health Care entity should be driven by the “MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities”
- https://opwdd.ny.gov/system/files/documents/2020/04/molst-checklist-opwdd-fillable.pdf

SCPA 1750-b Surrogate Prioritized List

- In order of priority
  - a. 17-A guardian
  - b. actively involved spouse
  - c. actively involved parent
  - d. actively involved adult child
  - e. actively involved adult sibling
  - f. actively involved family member
  - g. Willowbrook CAB (full representation)
  - h. Surrogate Decision Making Committee (MHL Article 80)

Key Points

- Special end-of-life decision making requirements exist for patients with developmental disabilities based on SCPA 1750-b
- Capacity is the assessment of the patient's ability to understand the consequences of a decision
- A person's decisional capacities may vary depending on the nature and complexity of the decision involved
- For a patient with I/DD, special requirements must be met by either the attending or concurring physician or licensed psychologist
- The OPWDD checklist must be completed before the physician signs the MOLST
- The completed OPWDD checklist should be attached to a completed MOLST form

Resources

- Grisso, T. & Appelbaum, P.S. (1998). Assessing competence to consent to treatment: A guide for physicians and other health professionals. New York: Oxford University Press
- OPWDD's Health Care Decisions Webpage:
  - https://opwdd.ny.gov/providers/health-care-decisions
- OPWDD Checklist:
  - https://opwdd.ny.gov/system/files/documents/2020/04/molst-checklist-opwdd-fillable.pdf
- Surrogate Decision Making Committee (SDMC) forms and information:
  - https://www.justicecenter.ny.gov/SDMC