End of Life Decisions for the Surrogate Decision Making Committee Volunteer Training

February 23, 2018
End of Life Decisions

Date: February 23, 2018, 2:00 P.M. – 5:00 P.M.

Presenters: Deirdre Keating, Esq. and Laura Monthie, BS, RN, LSCW-R

Agenda

1:30pm – 2:00pm  Registration
2:00pm – 2:30pm  Legal Background
SDMC and Health Care Decisions Act

2:30pm – 3:00pm  Health Care Decisions Act
Provisions and Amendments
Life Sustaining Treatment

3:00pm – 3:10pm  Break

3:10pm 4:00pm  Role of the Surrogate Decision Maker
Role of the Attending Physician
Complying with the Law
SDMC EOL Case Forms

4:00pm – 4:10pm  Break

4:10pm – 5:00pm  Evaluating Capacity
Burden of Treatment
Surrogate Court Procedure Act § 1750-b Process
SDMC End of Life Hearing
SDMC EOL Hearing Record
MOLST Legal Requirements
Hospice Admission
End of Life Decisions for the Surrogate Decision Making Committee Volunteer Training

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SPEAKER BIOGRAPHIES

DEIRDRE KEATING, ESQ., is the Director of the Criminal Background Check Unit at the New York State Justice Center for the Protection of People with Special Needs. Among other duties, this Unit is responsible for reviewing the criminal history and making employment suitability determinations on those persons applying to work with vulnerable populations served by providers under the jurisdiction of the Justice Center. Prior to joining the Justice Center, Ms. Keating served as a Senior Attorney with the New York State Division of Criminal Justice Services with a primary focus on access to criminal history information issues. After graduating from Albany Law School and working in private practice, she joined the Counsel’s Office of the New York State Department of Correctional Services and worked in the Legislative and Intergovernmental Affairs Unit. Ms. Keating has also served as the Town Prosecuting Attorney for Ravena, NY, and the Planning and Zoning Attorney for Rensselaerville, NY. Her undergraduate degree is from the State University of New York at Albany. She is admitted to practice in New York.

LAURA MONTHIE, LCSW-R, B.S., RN, began her career as a nurse which naturally transitioned into social work twenty years ago through her work with medically involved children and advocacy for persons with disabilities. As the training coordinator for the Surrogate Decision-Making Committee (SDMC) program of the Justice Center for the Protection of People with Special Needs, Ms. Monthie is responsible for providing outreach to providers as well as training for the volunteer panel members who serve the SDMC program across the state for both major medical procedures and end of life care decisions. She received an AAS in nursing from Maria College, a BS in nursing from SUNY Polytechnic Institute, and a BA in psychology and an MSW from the University at Albany. Ms. Monthie is a registered nurse and a licensed clinical social worker.
Surrogate Decision Making Committee
CLE, End of Life Care Decisions Volunteer Training
2.23.18
Agenda

• Legal Background
  – SDMC and Health Care Decisions Act
  – Legislative Intent

• Health Care Decisions Act
  – Provisions and Protections

• Complying with the Law
  – SDMC EOL Case Forms
  – The Hearing
  – SDMC EOL Hearing Record
Legal Background:
SDMC &
The Health Care
Decisions Act
SDMC Decision-Making Authority

Surrogate Decision-Making Committee Program
NYS MHL Article 80 Surrogate Decision-Making for Medical Care and Treatment
14 NYCRR Part 710 Procedures of the SDMC

Article 17-A, SCPA 1750-b
• Decisions to withhold and/or withdraw life-sustaining treatment
• SDMC added to the list of possible surrogate decision-makers effective 1/1/2009
Legal Background

Basic Right to Consent- Personal autonomy to determine what may be done with his/her body
  • Sholendorff vs. Society of NY Hospital, 211 NY 125 (1914)

Right to refuse treatment if competent
  • Fosmire v. Nicoleau, 75 NY2d 218 (1990)
Legal Background

- In re Westchester County Med. Ctr. ex rel. O'Connor, 72 NY2d 517 (1988)
Legal Background

Storar

• A parent /guardian does not have the right to refuse treatment on behalf of a person who has never had the ability to communicate their wishes

• People who never had the ability to communicate their wishes were deemed to want treatment
Legal Background

O’Connor

• No firm commitment to decline treatment while competent
• Decision narrowed to patient’s expressed intent
• Requires clear and convincing standard
Legal Background

Cruzan

• The state is warranted in establishing rigorous procedures for refusal of medical treatment for persons who are incompetent.
Legal Background
Blouin

- Shelia Pouliot admitted to hospital 12/99
- Family asked to withhold treatment
- Treatment ended, began again, ended
- Appeal to be heard 3/7/00
- Ms. Pouliot died 3/4/00
Legal Background
Blouin

- Alice Blouin, sister, filed lawsuit alleging negligence, unlawful practice of medicine, battery, intentional or reckless infliction of emotional distress and anxious and Constitutional violations
Legal Background: Prior to the HCDA

• New York State did not allow removal from life support/ withdrawal of Life Sustaining Treatment (LST) without a Health Care Proxy

• New York State required LST to continue if an individual had never competently expressed a desire NOT to be treated in such a way
Health Care Decisions Act

SCPA § 1750-b
In 2002, 1750-b of the SCPA was created to grant authority to Article 17-A guardians to make health care decisions regarding life sustaining treatment for persons with intellectual disabilities.
HCDA: Subsequent Chapters

- 17-A guardians for persons with ID *Chapter 500 Laws of 2002*
- Corporate guardians *Chapter 232 Laws of 2003*
- 17-A guardians for person with DD *Chapter 744 Laws of 2005*
- Family members *Chapter 105 Laws of 2007*
- SDMC *Chapter 262 Laws of 2008*
- Consumer Advisory Board for Willowbrook *Chapter 8 of Laws of 2010*
Legal Background
In re M.B., 6 NY3d 437 (2006)

• Whether the HCDA applies only to guardians appointed after March 2003 effective date; or

• whether it also effects the authority of guardians serving before March 2003
Health Care Decisions Act
Applies to All Surrogate Decision-Makers for Persons with ID/DD, Including Family Members, Guardians, and the SDMC

Same rigorous standards must be followed by all guardians, including family members and SDMC
Hierarchy of Decision Makers/Possible 1750-b Surrogates:

1. Court appointed guardian with authority to make health care decisions
2. Actively involved spouse
3. Actively involved parent
4. Actively involved adult child
5. Actively involved adult sibling
6. Actively involved other adult family member
7. The Consumer Advisory Board for Willowbrook Class
8. A Surrogate Decision-Making Committee
9. A Court of Competent Jurisdiction

OPWDD Regulation 14 NYCRR Part 633.10; SCPA 1750-b (1)
SDMC Jurisdiction for Withdrawal/Withholding of Life Sustaining Treatment

SDMC authority is restricted to individuals diagnosed with an intellectual or developmental disability.

The individual does not need to have received services from OPWDD, only a diagnosis of ID/DD is required to qualify for SDMC.
Health Care Decisions Act

Exceptions

Health Care Proxy
If the person has a valid HCP, the agent operates outside the scope of the HCDA process

Brain Death
HCDA process is not required in the event of brain death
Life-Sustaining Treatment

Life Sustaining Treatment is any treatment which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period.

FHCDA [PHL 2994-a 19]  SCPA 1750-b 4  HCP Statute [PHL 2980 9-a]
Life-Sustaining Treatment Includes

- Cardiopulmonary Resuscitation (CPR)
- Intubation/Ventilation
- Artificial nutrition and hydration (NG, PEG, G-tube)
- Dialysis
- Use of antibiotics, inotropes, pressors, chemotherapy
- Blood transfusions
- Any other treatment the physician deems to be LST
The Role of the Surrogate Decision-Maker in 1750-b

- Advocate for the full and efficacious provision of health care, including LST

- All treatment decisions made are based on the person’s best interests, and when known, the person’s wishes including moral and religious beliefs

*SCPA 1750-b (2)(a); SCPA 1750-b (2)(b)*
The Role of the Surrogate Decision-Maker in 1750-b

Best Interest Decisions are based upon:

- The dignity and uniqueness of the person
- Preservation, improvement or restoration of health
- Relief of suffering
- Consideration of the unique nature of artificial nutrition/hydration
- The entire medical condition of the person

SCPA 1750-b (2)(a); SCPA 1750-b (2)(b)
The Role of the Attending Physician

Capacity Evaluation

SCPA 1750-b(4)(a)(b)

Medical Condition

SCPA 1750-b(4)(b)

Notification of the Decision

SCPA 1750-b(4)(e)
The Role of the Attending Physician

Notifications of the Decision

- The Patient
- Agency CEO or State Operations Office or the Commissioner of OPWDD if person doesn’t reside in a voluntary/state operated residence (e.g., Nursing Home)
- MHLS

SCPA 1750-b(4)(e)
How Does SDMC Incorporate the HCDA?
Complying with the HCDA: The SDMC Process

• SDMC forms require the same HCDA medical and capacity certifications

• Efforts to determine any moral and/or religious beliefs or opinions of the patient

• Notifications are made following the SDMC hearing decision

• Follows 1750-b decision-making standard

• The SDMC decision is issued in writing and witnessed

• Objection rights and Appeal Process for SDMC follows the HCDA
Complying with the HCDA: SDMC Forms

- Declaration for End of Life Care (SDMC Form 300)
- Certification on Capacity for End of Life Care (SDMC Form 310)
- Attending Physician and Concurring Physician Certification for End of Life Care (SDMC 320 AB)
- Supplemental Medical Information for End of Life Care (SDMC Form 330)
Two Capacity Certifications: SDMC Form 310

• The attending physician and consulting physician and/or licensed psychologist, must confirm that the person lacks capacity

• Both clinicians must document the cause, nature, extent and probably duration of the person’s incapacity

• One evaluator must have specialized experience with ID/DD

SCPA 1750-b(4)(a)(b)
Special Criteria for Evaluating Capacity

One of the evaluators must meet one of the following criteria:

• Employed by a Development Disabilities Services Office

• Employed for a minimum of two years in a facility or program operated, licensed, or authorized by OPWDD

• Approved by the OPWDD Commissioner

Certification on Capacity (Form 310)
SCPA 1750-b(4)(a)(b)
Attending and Concurring Physician Certification for End of Life Care: SDMC Form 320 AB

Two physicians certify that the patient has:

• A terminal condition; or

• Permanent unconsciousness; or

• Requires life-sustaining treatment, is irreversible and will continue indefinitely.

SCPA 1750-b(4)(b)
Two Physicians Certify the Extraordinary Burden of Continued LST: SDMC Form 320 AB

In light of:

• The person’s medical condition, other than the person’s intellectual or developmental disability;

and

• The expected outcome of the LST, aside from a person’s intellectual or developmental disability

SCPA 1750-b(4)(b) B
The Life Sustaining Treatment to be Withheld/Withdrawn: SDMC Form 320 AB

- CPR (DNR)
- Mechanical Ventilation (DNI)
- Antibiotics
- Hospitalizations
- Vasopressors
- Artificial Nutrition and/or Hydration
The Extraordinary Burden of Continued Life-Sustaining

Considerations of the impact on the patient, in light of the medical condition and expected outcome

• Is treatment painful?
• Is it futile?
• Is it without benefit?
• Does it fail to improve quality of life?

Attending and Concurring Physician Certification (Form 320-AB)
SCPA 1750-b(4)(b)
Burden of Treatment: Considerations

- Pain and suffering outweighs the benefits of LST
- Would the proposed treatment merely prolong the person’s suffering?
- Is there any net benefit to the person’s functioning or quality of life?
- Is continued treatment futile?
- Any hope of recovery or restoration of function?

14 NYCRR Part 710.2 (b)
Artificial Nutrition and Hydration is Considered Separately

To withdraw or withhold artificially provided nutrition or hydration, two physicians must also agree there is:

• No reasonable hope of maintaining life

OR

• The artificially provided nutrition and/or hydration poses an extraordinary burden

Certification of Medical Need Forms 320 AB

SCPA 1750-b(4)(b)(iii)
Decision Making Standard: Attestation by the Declarant

No health care decision shall be influenced:

• By a presumption that an individual with an ID or DD is not entitled to the full and equal rights, protection, respect, medical care and dignity afforded to persons without ID or DD; Or by

• Financial considerations of the guardian, health care provider, or any other party

Declaration for End of Life Care Form 300

*SCPA 1750-b (2)(a); SCPA 1750-b(2)(c)*
HCDA Special Protections

• Not intended to permit suicide, assisted suicide or euthanasia
• Guardian/decision maker cannot consent to any act or omission the patient could not consent to if capacitated
• All advocacy and health care decision-making is solely and exclusively based on the best interests of the patient

SCPA 1750-b(1); SCPA 1750-b (2)(a)
SDMC Decision is Issued in Writing

Issued on SDMC Form 380-A

• Signed by the panel chairperson and witnessed by the SDMC representative at the hearing
• Consent is valid for DNR/DNI and other orders to withhold or withdraw LST
• All interested parties receive a copy
• There is no expiration date

SCPA 1750-b(4)(c)
Attending Physician Notifications Include:

- The individual
- Mental Hygiene Legal Services (MHLS)
- OPWDD State Operations Office Director or the agency CEO of the residential provider;
  
or
- The Commissioner of OPWDD or Designee

SCPA 1750-b(4)(e)
Notifications

Attending Physician provides notification following the SDMC hearing:

- To **Withhold** treatment - may be implemented after notifications have been made
- To Withdraw treatment- attending physician must wait at least 48 Hours before **Withdrawing** Treatment

*SCPA 1750-b (4)(e)*
Right to Object the Decision

• The Individual
• Parent or Sibling
• Attending Physician
• Any other Health Care Practitioner providing services to the individual
• Agency executive director/CEO; or DDSO Director
• Mental Hygiene Legal Services (MHLS)
• Commissioner of OPWDD or Designee

SCPA 1750-b (5)
Objection Process

• Objection may be issued orally or in writing
• Decision to withhold or withdraw treatment suspended until objection is resolved
• Objecting party must notify guardian (in this case SDMC) and other parties identified in SCPA1750-b(5)(a)
• A special proceeding may commence in a court of competent jurisdiction

SCPA 1750-b (5)(6)
The SDMC End of Life Hearing
Hearing Participants

- Individual *
- Declarant, Agency, Hospital Staff
- An attending physician in-person or by phone
- Four Panel Members
- Any Interested Parties or Correspondents
- Mental Hygiene Legal Services (MHLS)
- Local SDMC Coordinator

*The individual will be visited by at least one panel member prior to the hearing*
Panel Procedures

- EOL is almost always Expedited
- Review the case information prior to the hearing
- The hearing is typically held in the hospital but could be held at the patient’s home
- 1-2 panel members will visit the patient
- Testimony on Capacity-Authorized Surrogate-Best Interests
- 1750-b criteria is entered into the hearing record by testimony
- Decision is issued in writing
The Hearing Record Establishes:

- The Lack of Capacity to make the decision and the Lack of a Surrogate to act on their behalf
- Moral or religious beliefs expressed by the patient
- The Medical Condition
- The Life-Sustaining Treatment to be withheld/withdrawn
- The Extraordinary Burden of the Life-Sustaining Treatment
- The extraordinary burden of artificial nutrition/hydration
SDMC End of Life Hearing

Opening statement is read - identification of all present and participating by phone - swearing in witnesses

- The two panel members who visited the patient will objectively state on the record what they observed when they visited the patient, and objectively make statements about what they felt the capacity of the individual was based on the information that they were able to elicit from the patient.
- Residential staff and correspondents provide testimony concerning the person’s baseline functioning, daily routine, previous and present level of functioning; and any moral or religious beliefs expressed by the patient.
- Testimony establishing the lack of a surrogate
SDMC End of Life Hearing  cont’d

<table>
<thead>
<tr>
<th>Best Interests</th>
<th>Medical Condition</th>
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| Preponderance of the Evidence Decision- Making Standard | The panel must obtain testimony to enter the qualifying medical condition on the record.  
(See page 2 of the Attending and Concurring Physician Certification)  
- Terminal Condition, or  
- Permanent Unconsciousness, or  
- A Medical Condition that is irreversible, requires LST and will continue indefinitely |

What is the LST to be Withheld/Withdrawn?
The Extraordinary Burden of the LST

- What is the LST that is recommended to be withdrawn/withheld?
- Why would the LST present an extraordinary burden in light of the patient’s qualifying medical condition?
- What is the medical condition and prognosis?
- Likely outcome of LST if continued?

Extraordinary Burden Artificial Nutrition and Hydration

- The Burden of Artificial Nutrition and Hydration is always a separate discussion.
- Testimony to support the reasons why artificial nutrition and hydration presents an extraordinary burden for the patient.
SDMC: Best Interests Considerations

- Risks, benefits, alternatives, burden of treatment
- Relief of suffering; pain with and without treatment
- Preservation or restoration of function; prognosis
- Improvement in the quality of the patient’s life
- Personal beliefs and values of the patient

MHL Article 80.3 (d)
14 NYCRR Part 710.2(b)
Best Interests Considerations

- The dignity and uniqueness of every person
- Preservation, improvement or restoration of health
- Relief of suffering by means of palliative care and pain management
- The nature of artificially provided nutrition or hydration
- The entire medical condition of the patient

SCPA 1750-b (2)(b)
Case Examples

DNR/DNI

Complex Medical Situations

Withdrawal/Withholding of Artificial Nutrition and Hydration
If SDMC does not Consent to Withhold/Withdraw LST

Any party may:

• Submit to the committee a declaration for non-emergency medical treatment; or

• Immediately resubmit an EOL case with new information

NYCRR Part 710.4 (c) (9) and 710.4 (c) (10)
MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities

All life sustaining treatment decisions must have a copy of the MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities attached.
Hospice Admission Forms

• SDMC Consent is valid for Hospice
• Federal and State Laws govern Hospice
• SDMC Panel Chairperson may sign Hospice admission forms relative to consent for hospice treatment and receipt of notice of patient rights
• Payment authorization for Hospice services shall be the responsibility of the director or designee of the patient’s residential program per MHL 33.03
SDMC Contact Information

Main Phone: 518-549-0328

Main Fax: 518-549-0460

www.justicecenter.ny.gov
§ 1750-b. Health care decisions for intellectually disabled persons

1. Scope of authority. Unless specifically prohibited by the court after consideration of the determination, if any, regarding an intellectually disabled person's capacity to make health care decisions, which is required by section seventeen hundred fifty of this article, the guardian of such person appointed pursuant to section seventeen hundred fifty of this article shall have the authority to make any and all health care decisions, as defined by subdivision six of section twenty-nine hundred eighty of the public health law, on behalf of the intellectually disabled person that such person could make if such person had capacity. Such decisions may include decisions to withhold or withdraw life-sustaining treatment. For purposes of this section, "life-sustaining treatment" means medical treatment, including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period.

Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. The provisions of this article are not intended to permit or promote suicide, assisted suicide or euthanasia; accordingly, nothing in this section shall be construed to permit a guardian to consent to any act or omission to which the intellectually disabled person could not consent if such person had capacity. (a) For the purposes of making a decision to withhold or withdraw life-sustaining treatment pursuant to this section, in the case of a person for whom no guardian has been appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article, a "guardian" shall also mean a family member of a person who

(i) has an intellectual disability, or

(ii) has a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability. Qualified family members shall be included in a prioritized list of said family members pursuant to regulations established by the commissioner of mental retardation and developmental disabilities. Such family members must have a significant and ongoing involvement in a person's life so as to have sufficient knowledge of their needs and, when reasonably known or ascertainable, the person's wishes, including moral and religious beliefs. In the case of a person who was a resident of the former Willowbrook state school on March seventeenth, nineteen hundred seventy-
two and those individuals who were in community care status on that date and subsequently returned to Willowbrook or a related facility, who are fully represented by the consumer advisory board and who have no guardians appointed pursuant to this article or have no qualified family members to make such a decision, then a "guardian" shall also mean the Willowbrook consumer advisory board. A decision of such family member or the Willowbrook consumer advisory board to withhold or withdraw life-sustaining treatment shall be subject to all of the protections, procedures and safeguards which apply to the decision of a guardian to withhold or withdraw life-sustaining treatment pursuant to this section. In the case of a person for whom no guardian has been appointed pursuant to this article or for whom there is no qualified family member or the Willowbrook consumer advisory board available to make such a decision, a "guardian" shall also mean, notwithstanding the definitions in section 80.03 of the mental hygiene law, a surrogate decision-making committee, as defined in article eighty of the mental hygiene law. All declarations and procedures, including expedited procedures, to comply with this section shall be established by regulations promulgated by the commission on quality of care and advocacy for persons with disabilities.

(b) Regulations establishing the prioritized list of qualified family members required by paragraph (a) of this subdivision shall be developed by the commissioner of mental retardation and developmental disabilities in conjunction with parents, advocates and family members of persons who are mentally retarded. Regulations to implement the authority of the Willowbrook consumer advisory board pursuant to paragraph (a) of this subdivision may be promulgated by the commissioner of the office of mental retardation and developmental disabilities with advice from the Willowbrook consumer advisory board.

(c) Notwithstanding any provision of law to the contrary, the formal determinations required pursuant to section seventeen hundred fifty of this article shall only apply to guardians appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article.

2. Decision-making standard.

(a) The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the intellectually disabled person and, when reasonably known or ascertainable with reasonable diligence, on the intellectually disabled person's wishes, including moral and religious beliefs.

(b) An assessment of the intellectually disabled person's best interests shall include consideration of:

(i) the dignity and uniqueness of every person;
(ii) the preservation, improvement or restoration of the intellectually disabled person's health;
(iii) the relief of the intellectually disabled person's suffering by means of palliative care and pain management;
(iv) the unique nature of artificially provided nutrition or hydration, and the
effect it may have on the intellectually disabled person; and

(v) the entire medical condition of the person.

(c) No health care decision shall be influenced in any way by:

(i) a presumption that persons with mental retardation are not entitled to the full
and equal rights, equal protection, respect, medical care and dignity afforded to persons
without intellectual disabilities or developmental disabilities; or

(ii) financial considerations of the guardian, as such considerations affect the
guardian, a health care provider or any other party.

3. Right to receive information. Subject to the provisions of sections 33.13 and 33.16
of the mental hygiene law, the guardian shall have the right to receive all medical
information and medical and clinical records necessary to make informed decisions
regarding the intellectually disabled person's health care.

4. Life-sustaining treatment. The guardian shall have the affirmative obligation to
advocate for the full and efficacious provision of health care, including life-sustaining
treatment. In the event that a guardian makes a decision to withdraw or withhold life-
sustaining treatment from a intellectually disabled person:

(a) The attending physician, as defined in subdivision two of section twenty-nine
hundred eighty of the public health law, must confirm to a reasonable degree of medical
certainty that the intellectually disabled person lacks capacity to make health care
decisions. The determination thereof shall be included in the intellectually disabled
person's medical record, and shall contain such attending physician's opinion regarding
the cause and nature of the intellectually disabled person's incapacity as well as its
extent and probable duration. The attending physician who makes the confirmation
shall consult with another physician, or a licensed psychologist, to further confirm
the intellectually disabled person's lack of capacity. The attending physician who
makes the confirmation, or the physician or licensed psychologist with whom the
attending physician consults, must (i) be employed by a developmental disabilities
services office named in section 13.17 of the mental hygiene law or employed by the
office for people with developmental disabilities to provide treatment and care to
people with developmental disabilities, or (ii) have been employed for a minimum of
two years to render care and service in a facility or program operated, licensed or
authorized by the office of mental retardation and developmental disabilities, or (iii) have
been approved by the commissioner of mental retardation and developmental
disabilities in accordance with regulations promulgated by such commissioner.
Such regulations shall require that a physician or licensed psychologist possess
specialized training or three years' experience in treating intellectual disabilities. A
record of such consultation shall be included in the intellectually disabled person's
medical record.

(b) The attending physician, as defined in subdivision two of section twenty-nine
hundred eighty of the public health law, with the concurrence of another physician
with whom such attending physician shall consult, must determine to a reasonable
degree of medical certainty and note on the intellectually disabled person's chart that:

(i) the intellectually disabled person has a medical condition as follows:

A. a terminal condition, as defined in subdivision twenty-three of section twenty-nine hundred sixty-one of the public health law; or

B. permanent unconsciousness; or

(ii) the life-sustaining treatment would impose an extraordinary burden on such person, in light of:

A. such person's medical condition, other than such person's intellectual disability; and

B. the expected outcome of the life-sustaining treatment, notwithstanding such person's intellectual disability; and

(iii) in the case of a decision to withdraw or withhold artificially provided nutrition or hydration:

A. there is no reasonable hope of maintaining life; or

B. the artificially provided nutrition or hydration poses an extraordinary burden.

(c) The guardian shall express a decision to withhold or withdraw life-sustaining treatment either:

(i) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and

presented to the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or

(ii) orally, to two persons eighteen years of age or older, at least

one of whom is the intellectually disabled person's attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law.

(d) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, who is provided with the decision of a guardian shall include the decision in the intellectually disabled person's medical chart, and shall either:

(i) promptly issue an order to withhold or withdraw life-sustaining treatment from the mentally retarded person, and inform the staff responsible for such person's care, if any, of the order; or

(ii) promptly object to such decision, in accordance with subdivision five of this section.
(e) At least forty-eight hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment, the attending physician shall notify:

(i) the intellectually disabled person, except if the attending physician determines, in writing and in consultation with another physician or a licensed psychologist, that, to a reasonable degree of medical certainty, the person would suffer immediate and severe injury from such notification. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, shall:

A. be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or

B. have been employed for a minimum of two years to render care and service in a facility operated, licensed or authorized by the office of Persons with developmental disabilities, or

C. have been approved by the commissioner of OPWDD in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years’ experience in treating mental retardation. A record of such consultation shall be included in the intellectually disabled person's medical record;

(ii) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office of Persons with Developmental Disabilities, the chief executive officer

of the agency or organization operating such facility and the mental hygiene legal service; and

(iii) if the person is not in and was not transferred from such a facility or program, the commissioner of OPWDD, or his or her designee.

5. Objection to health care decision.

(a) Suspension. A health care decision made pursuant to subdivision four of this section shall be suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the intellectually disabled person, in the event of an objection to that decision at any time by:

(i) the intellectually disabled person on whose behalf such decision was made; or

(ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the intellectually disabled person; or

(iii) the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or

(iv) any other health care practitioner providing services to the intellectually disabled person, who is licensed pursuant to article one hundred thirty-one, one hundred thirty-one-B, one hundred thirty-two, one hundred thirty-three, one hundred thirty-
six, one hundred thirty-nine, one hundred forty-one, one hundred forty-three, one hundred forty-four, one hundred fifty-three, one hundred fifty-four, one hundred fifty-six, one hundred fifty-nine or one hundred sixty-four of the education law; or

(v) the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section; or

(vi) if the person is in or was transferred from a residential facility or program operated, approved or licensed by the Office of Persons with Developmental Disabilities (OPWDD), the mental hygiene legal service; or

(vii) if the person is not in and was not transferred from such a facility or program, the commissioner of the Office of Persons with Developmental Disabilities (OPWDD), or his or her designee.

(b) Form of objection. Such objection shall occur orally or in writing.

(c) Notification. In the event of the suspension of a health care decision pursuant to this subdivision, the objecting party shall promptly notify the guardian and the other parties identified in paragraph (a) of this subdivision, and the attending physician shall record such suspension in the intellectually disabled person’s medical chart.

(d) Dispute mediation. In the event of an objection pursuant to this subdivision, at the request of the objecting party or person or entity authorized to act as a guardian under this section, except a surrogate decision making committee established pursuant to article eighty of the mental hygiene law, such shall be referred to a dispute mediation system, established pursuant to section two thousand nine hundred seventy-two of the public health law or similar entity for mediating disputes in a hospice, such as a patient’s advocate’s office, hospital chaplain’s office or ethics committee, as described in writing and adopted by the governing authority of such hospice, for non-binding mediation. In the event that such dispute cannot be resolved within seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a dispute, the objection shall proceed to judicial review pursuant to this subdivision. The party requesting mediation shall provide notification to those parties entitled to notice pursuant to paragraph (a) of this subdivision.

6. Special proceeding authorized. The guardian, the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section, the mental hygiene legal service (if the person is in or was transferred from a residential facility or program operated, approved or licensed by the Office for People with Developmental Disabilities) or the commissioner OPWDD or his or her designee (if the person is not in and was not transferred from such a facility or program) may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this section, including objecting to the withdrawal or withholding of life-sustaining treatment because such withdrawal or withholding is not in accord with the criteria set forth in this section.
7. Provider’s obligations.

(a) A health care provider shall comply with the health care decisions made by a guardian in good faith pursuant to this section, to the same extent as if such decisions had been made by the intellectually disabled person, if such person had capacity.

(b) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require a private hospital to honor a guardian’s health care decision that the hospital would not honor if the decision had been made by the intellectually disabled person, if such person had capacity, because the decision is contrary to a formally adopted written policy of the hospital expressly based on religious beliefs or sincerely held moral convictions central to the hospital’s operating principles, and the hospital would be permitted by law to refuse to honor the decision if made by such person, provided:

(i) the hospital has informed the guardian of such policy prior to or upon admission, if reasonably possible; and

(ii) the intellectually disabled person is transferred promptly to another hospital that is reasonably accessible under the circumstances and is willing to honor the guardian’s decision. If the guardian is unable or unwilling to arrange such a transfer, the hospital’s refusal to honor the decision of the guardian shall constitute an objection pursuant to subdivision five of this section.

(c) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require an individual health care provider to honor a guardian’s health care decision that the individual would not honor if the decision had been made by the intellectually disabled person, if such person had capacity, because the decision is contrary to the individual’s religious beliefs or sincerely held moral convictions, provided the individual health care provider promptly informs the guardian and the facility, if any, of his or her refusal to honor the guardian’s decision. In such event, the facility shall promptly transfer responsibility for the intellectually disabled person to another individual health care provider willing to honor the guardian’s decision. The individual health care provider shall cooperate in facilitating such transfer of the patient.

(d) Notwithstanding the provisions of any other paragraph of this subdivision, if a guardian directs the provision of life-sustaining treatment, the denial of which in reasonable medical judgment would be likely to result in the death of the intellectually disabled person, a hospital or individual health care provider that does not wish to provide such treatment shall nonetheless comply with the guardian’s decision pending either transfer of the intellectually disabled person to a willing hospital or individual health care provider, or judicial review.

(e) Nothing in this section shall affect or diminish the authority of a surrogate decision-making panel to render decisions regarding major medical treatment pursuant to article eighty of the mental hygiene law.
8. Immunity.

(a) Provider immunity. No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring reasonably and in good faith a health care decision by a guardian, or for other actions taken reasonably and in good faith pursuant to this section.

(b) Guardian immunity. No guardian shall be subjected to criminal or civil liability for making a health care decision reasonably and in good faith pursuant to this section.