ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)
Notifications: Who, What, When and Why

Presenters

Eileen Zibell, Esq.
Associate Attorney, NYS Office For People With Developmental Disabilities (OPWDD)

Sheila Shea, Esq.
Director, State of New York Supreme Court, Appellate Division, Third Judicial Department, Mental Hygiene Legal Services (MHLS)

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Learning Objectives

• Define who needs to be notified based on the individual’s residential setting

• Describe timing differences between withholding and withdrawing life-sustaining treatments

• Explain why notifications are required before the physician signs the MOLST
Life Sustaining Treatment (LST)

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. Includes CPR, mechanical ventilation, hemodialysis, and artificial nutrition and hydration.

SCPA 1750-b(1)
Any individual with capacity can make their own health care decisions.

Any individual with capacity can execute a health care proxy if they can understand that they are delegating to another (an agent) the authority to make health care decision for when they lack capacity (temporarily or permanently) to make a medical decision.

In writing, two witnesses. Agent cannot witness.
**I/DD Individuals without Capacity**

If an I/DD individual who previously had capacity executed a health care proxy:

the agent can make decisions within the parameters of the power given to them.

But what if there is no agent?

- no HCP or agent not available
- or individual never had the capacity to appoint an agent
Legal Framework

“Health Care Decisions Act” (for persons who are intellectually disabled)

Codified at Surrogate’s Court Procedure Act 1750-b; Effective March 16, 2003;

Reformed law to relax strict common law rules which required clear and convincing evidence of what the individual would have wanted in this situation in order to withhold or withdraw LST;
Legally authorized surrogates (OPWDD checklist, step 1)

may make decisions to withhold or withdraw life sustaining treatment for patients with I/DD who lack capacity (OPWDD checklist, step 2),

but compliance with requirements in steps 3 and 4 of the OPWDD checklist is required.

Notice requirements are included in step 5 of the OPWDD checklist.
Review - Legally Authorized 1750b Surrogates

1. Court appointed guardians with authority to make healthcare decisions.
3. Actively involved parent.
4. Actively involved adult child, sibling, family member.
5. Consumer Advisory Board (Willowbrook Class).
   • Applies to patients without family members or other legally authorized surrogates.
Review - Responsibility of Surrogates

Advocate for efficacious treatment.

Base decisions on best interests, and when known, the person’s wishes including moral and religious beliefs.

Statutory best interest considerations include - dignity and uniqueness of the person, preserve, improve or restore health; relief from suffering.

SCPA 1750-b (2) & (4)
Role of Physician - Capacity

Attending physician determines if patient has capacity to make the decisions under consideration.

Arranges for a concurring determination of capacity by a physician or licensed psychologist who meets the employment/experience requirements in step 3 of the OPWDD checklist.
Role of Physician - Medical Criteria

Attending/concurring physician determines:
1. patient has a terminal condition; OR
2. is permanently unconscious; OR
3. has a medical condition other (other than a developmental disability) that is irreversible and will continue indefinitely; (COPD, dementia, for example)
   • AND, the proposed treatment would impose an extraordinary burden to the individual
Extraordinary Burden-Considerations

The person’s overall medical condition, other than the person’s developmental disability;

The expected outcome of treatment; notwithstanding the person’s developmental disability

SCPA 1750-b(4)(b)
Artificial Nutrition and Hydration

Additional requirement of finding:

• ANH itself poses an extraordinary burden to the person or;

• there is no reasonable hope of maintaining life

SCPA 1750-b(4)(b)
## Oversight

<table>
<thead>
<tr>
<th>Residents of a facility operated or licensed by OPWDD</th>
<th>SCPA 1750-b LST decisions are subject to oversight by the facility director and MHLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who do not reside in a certified setting</td>
<td>SCPA LST decisions are subject to oversight by OPWDD</td>
</tr>
<tr>
<td>How is Oversight Exercised?</td>
<td>By providing notice of LST decisions to facility director and MHLS or OPWDD Commissioner, as appropriate</td>
</tr>
<tr>
<td>Best Practice</td>
<td>In practice, notice often provided by sending completed OPWDD legal requirements checklist to the appropriate parties.</td>
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</table>
Mental Hygiene Legal Service

- Agency of the Appellate Divisions of State Supreme Court
- Operates pursuant to an enabling law codified at Mental Hygiene Law sections 47.01 & 47.03
- There are four appellate divisions so there are four MHLS departments
- Website with [MHLS contacts in every county](#)
<table>
<thead>
<tr>
<th>Notice requirements</th>
<th>For withdrawing LST</th>
<th>For withholding LST</th>
<th>Patient Notice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At least 48 hours before withdrawing LST (example, terminal/compassionate extubation)</td>
<td>As soon as possible if withholding LST (example, DNR/DNI, chemotherapy, dialysis)</td>
<td>Patient should be given notice of decision unless therapeutic exception applies</td>
</tr>
</tbody>
</table>
1. Recommendation for withdrawing or withholding LST
2. OPWDD checklist
   1. Capacity determination
   2. Concurring opinion
   3. Consent
   4. Care to be withdrawn/withheld
3. Notice
   1. to patient
   2. MHLS*, residential provider and/or OPWDD as appropriate
   *provide checklist, relevant medical records, proposed or draft MOLST.
4. If there are no objections - medical orders can be entered
Health Care Decision Resources

• OPWDD health care decisions webpage
• OPWDD checklist
• DOH 5003 MOLST Form
• eMOLST
OPWDD Checklist - criteria, notice

MOLST Legal Requirement
Checklist For People With Developmental Disabilities

LAST NAME/FIRST NAME

DATE OF BIRTH

ADDRESS

Note: Actual orders should be placed on the MOLST form with this completed checklist attached. Use this checklist as required for individuals with developmental disabilities (DD) who lack the capacity to make their own health care decisions and do not have a health care proxy. Medical decisions which involve the withholding or withdrawing of life sustaining treatment (LST) for individuals with DD who lack capacity and do not have a health care proxy must comply with the process set forth in the Health Care Decisions Act for persons with MR (HKSA § 1750-b (4)). Effective June 1, 2010, this includes the issuance of IDNR orders.

Step 1 - Identification of Appropriate 1750-b Surrogate from Prioritized List. Check appropriate category and add name of surrogate.

a. 17-A guardian
b. activity involved patient
c. activity involved adult sibling
d. activity involved adult child
e. activity involved adult sibling
f. activity involved family member
g. Wilberbrock CAB (full representation)
h. Surrogate Decision Making Committee (MR, Article 80)

Step 2 - 1750-b surrogate has a conversation or a series of conversations with the treating physician regarding possible treatment options and goals for care. Following these discussions, the 1750-b surrogate makes a decision to withdraw or withhold LST, either orally or in writing.

Specify the LST that is requested to be withdrawn or withheld:

Decision made orally:

Decision made in writing (must be dated, signed by surrogate, signed by 1 witness and given to attending physician):

Witness - Attending Physician

Second Witness - Attending Physician

LAST NAME/FIRST NAME

DATE OF BIRTH

Attending Physician

Concurring Physician

Step 3 - Confirm individual's lack of capacity to make health care decisions. Either the attending physician or the concurring physician or licensed psychologist must: (a) be employed by a DDSO; or (b) have been approved by OPWDD; or (c) have been approved by the commissioner of OPWDD; or (d) possess the qualifications necessary to provide care to the individual; or e. have at least 3 years in a facility or program operated, licensed or otherwise by OPWDD; or f. have been approved by the commissioner of OPWDD.

Attending Physician

Concurring Physician

Step 4 - Determination of Necessary Medical Criteria.

We have determined to a reasonable degree of medical certainty that both of the following conditions must be met:

(1) the individual has one of the following medical conditions:

a. a terminal condition (briefly describe ________)

or

b. permanent unconsciousness; or

c. a medical condition other than DD which requires LST, is irreversible and which will continue indefinitely (briefly describe ________)

AND

(2) the LST would impose an extraordinary burden on the individual in light of:

a. the person's medical condition other than DD (briefly explain ________)

b. the expected outcome of the LST, notwithstanding the person's DD (briefly explain ________)

If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn, one of the following additional factors must also be met:

a. there is no reasonable hope of maintaining life (explain ________)

b. the artificially provided nutrition or hydration poses an extraordinary burden (explain ________)

Step 5 - Notifications. At least 48 hours prior to the implementation of a decision to withdraw LST, or at the earliest possible time prior to a decision to withhold LST, the attending physician must notify the following parties:

the person with DD, unless therapeutic exception applies

notified on ________

if the person is in or was transferred from an OPWDD residential facility

Facility Director notified on ________

MHLS notified on ________

if the person is not in and was not transferred from an OPWDD residential facility

the director of the local DDSO notified on ________

Step 6 - I certify that the 1750-b process has been completed with the appropriate parties have been notified and no objections to the surrogate's decision remain unresolved.

Attending Physician

Date

Note: The MOLST form may ONLY be completed with the 1750-b surrogate after all 6 steps on this checklist have been completed.

Revised March 2020

Page 1
DOH 5003 MOLST Form

SECTION 1

Orders for Life-Sustaining Treatment and Future Hospitalization

When the Patient Has a Pulse and the Patient is Breathing

Do nothallucinate

Guidelines

If a decision is being made by a CP to be surrogate, a physician must sign the MOLST.

SVF-5003-DoS Rev 1/14

This MOLST form has been approved by the NTSBIR for use in 24 settings.
Objections

• Upon an objection the health care decision is suspended, pending mediation or judicial review.
• Objections may be lodged by patient, parent, adult sibling, other health care providers, facility director, MHLS, OPWDD Commissioner.
• Legally authorized surrogate should be notified of objection.
• In practice, objections are rare.

SCPA 1750-b(5)(b)
Why is notice required?

SCPA 1750-b serves to promote the rendition of efficacious treatment and dignity at the end of life.

Legislative judgment to provide oversight when rigid common law rule was relaxed for people with IDD who never had capacity to make their own decisions.

Physician notification promotes oversight objective to protect vulnerable population while enabling decisions to be made by a legally authorized surrogate to withhold or withdraw LST.