Health Care Decisions Act

For People With Intellectual/Developmental Disabilities

ECHO MOLST for individuals with I/DD
September, 2022

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

What is the Health Care Decisions Act?

- Contained in the Surrogate's Court Procedure Act (SCPA) section 1750-b – effective March 16, 2003
- Provided explicit authority for Article 17-A guardians of the person to make health care decisions
  * ***Including, for the first time, decisions to withhold or withdraw life sustaining treatment (LST)***
- Initially applied only to Article 17-A guardians of the person for persons with MR
- Subsequent Chapter Amendments
  - Corporate guardians of the person (like NYSARC)-2003
  - Guardians of person with DD -2005

What is Health Care Decisions Act? (cont.)

- Family members with significant and ongoing involvement in a person's life may make health care decisions to withhold or withdraw life-sustaining treatment – 2008
- Surrogate Decision Making Committees may make health care decisions, including decisions to withhold or withdraw life-sustaining treatment – 2009
- CAB for Willowbrook class members fully represented - 2010

Certifications Required to Support Guardianship Petition

- Either two licensed physicians or a licensed physician and licensed psychologist must certify:
  - that the person is incapable of managing themselves or their affairs because of ID or DD;
  - That their condition is permanent or likely to continue indefinitely; and
  - Whether or not the person has the capacity to make health care decisions.

Certifications Required to Support Guardianship Petition

- Statement regarding capacity to make health care decisions – new requirement
- Difficulty: It is an all or nothing proposition.
- Guidance – Unless person can make ALL healthcare decisions, assessment should indicate that individual cannot make healthcare decisions. Otherwise, guardian will not be granted the authority.

Included in New Guardianships

Article 17-A ID guardianship orders issued after 3/16/03 and applicable DD guardianship orders issued after 10/18/05 will include health care decision making authority, unless it is specifically excluded.

- Determined by Court of Appeals to apply retroactively to previously appointed 17-A guardians.

Decision Making Standard

- The surrogate has the **affirmative obligation** to **advocate** for the **full** and **efficacious provision of health care, including life sustaining treatment.**

- The surrogate must base all advocacy and health care decision making **solely** and **exclusively** on the **best interests** of the person and when reasonably know or ascertainable with reasonable diligence, on the **person's wishes**, including **moral** and **religious beliefs.**

Best Interest Factors

- Best interest of the person with I/DD:
  - The dignity and uniqueness of every person.
  - The preservation, improvement or restoration of the person's health.
  - The relief of the person's suffering by means of palliative care and pain management.
  - The unique nature of artificially provided nutrition or hydration and its effect on the person.
  - The entire medical condition of the person.

Improper Influences

- A surrogate's health care decisions may not be influenced by a presumption that the person with an Intellectual/Developmental Disability is not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to other persons.

- Financial consideration of the surrogate.

What about decisions regarding life-sustaining treatment?

- First – what is life sustaining treatment (LST)?
  - Life sustaining treatment means medical treatment **including CPR and artificial nutrition and hydration** which is sustaining life functions and without which according to reasonable medical judgment, the patient will die within a relatively short time period.

Prioritized Surrogate List

- Order of priority for decisions to withhold or withdraw LST
  - Article 17-A guardian
  - Qualified family member [14 NYCRR section 633.10(a)(7)(iv)]
    - Actively involved spouse
    - Actively involved parent
    - Actively involved adult child
    - Actively involved adult sibling
    - Actively involved adult family member
  - CAB (full representation of Willowbrook class member)
  - Surrogate Decision-Making Committee (under Justice Center for the Protection of People with Special Needs)

What about decisions regarding life-sustaining treatment?

- Brain death exception – DOH regulation 10 NYCRR §400.16.

- Steps to be followed when a “surrogate” makes a decision to withdraw or withhold life-sustaining treatment from a person with I/DD. (OPWDD checklist – step 2)
- OPWDD checklist includes the HCDA requirements and the process. Completion of the checklist is **critical**.

OPWDD Checklist Steps

- Step 1 – identification of appropriate surrogate. Residential provider should have this information.
- Step 2 – specify the LST that the surrogate is requesting to be withheld or withdrawn.
- Step 3 - attending physician must confirm that the person lacks capacity to make health care decisions.
- Step 3 - attending physician must consult with another physician or licensed psychologist to further confirm the person's lack of capacity (the concurring MD or licensed Psychologist must have specialized qualifications as indicated on the checklist)
- Step 4 - the attending physician, with the concurrence of another physician, must determine to a reasonable degree of medical certainty that **both** of the following sets of conditions are met:

Medical Conditions

1. the person with I/DD has one of the following medical conditions:
   - a terminal condition – an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year;
   - permanent unconsciousness; or,
   - a medical condition other than I/DD which requires life-sustaining treatment, is irreversible and which will continue indefinitely.

AND

Conditions

2. the life-sustaining treatment would impose an **extraordinary burden** on the person, in light of:
   - the person's medical condition (other than I/DD);
     and
   - the expected outcome of the life-sustaining treatment (notwithstanding the person's I/DD).
   - Extraordinary burden – not defined.
   - Individualized determination.
   - Important to note that the individual's medical condition must meet these requirements at the time the surrogate is making the decision.

In the case of a decision to withdraw or withhold artificially provided nutrition or hydration, one of the following additional factors must also be met:

- there is no reasonable hope of maintaining life;

or

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

In the event that the physician intends to issue an order to implement a decision of the "surrogate" to withdraw or withhold life-sustaining treatment, he or she must first notify certain parties (OPWDD checklist step 5)

- the person with I/DD (unless therapeutic exception applies); and
- Executive Director of OPWDD residential agency and MHLS;

  or

- OPWDD Commissioner (when the person was not receiving OPWDD residential services)
- Commissioner designated DDSO director to receive these notices [14 NYCRR section 633.10 (a)(7)(iii)]. Pre-dated DDSO/RO split.

Notifications

- If proposing to withdraw LST, must provide at least 48 hours notice
- If proposing to withhold LST, must provide notice “at the earliest possible time.”

7 Categories of people who may object to a decision of the "surrogate" to withhold or withdraw life-sustaining treatment:

- The person with I/DD
- A parent or adult sibling (substantial and continuous contact)
- The attending physician
- Any other health care practitioner providing services to the person
- The OPWDD agency Executive Director
- MHLS
- OPWDD Commissioner [or DDSO/RO director]

Objections

- Objections may be made orally or in writing
- Objection suspends decision of the “surrogate”, pending judicial review or dispute mediation (unless suspension is likely to result in the person’s death).
- Objecting party must notify ”surrogate” and other parties who could have objected if decision is suspended.

Certain parties are authorized to initiate a special proceeding in court to resolve any dispute arising under the law:

- the “surrogate”
- the attending physician
- the OPWDD DDSOO director or agency Executive Director
- MHLS
- OPWDD Commissioner or designee

Dispute Mediation

- May be requested by objecting party or surrogate (other than SDMC)
- Non-binding mediation
- If objection is withdrawn, surrogate's decision is implemented
- Law provides for objection to proceed to judicial review after 72 hours. However, does not indicate who must initiate.

Health Care Provider Obligations

- Doctors and hospitals are generally required to comply with health care decisions made by a "surrogate" in good faith.
- Private hospital exception for formally adopted written policies.
- Similar exception for individual health care providers.
- Immunity for providers and "surrogates"

Applicability of Family Health Care Decisions Act (FHCDA)

- Contained in the Public Health Law Article 29-CC
- Generally does not apply to persons with I/DD

Two exceptions:

(1) Individual is providing their own consent (DOH MOLST checklist # 1);

(2) Consent is being provided by the individual's health care agent, pursuant to a properly executed health care proxy (DOH MOLST checklist # 2).

Two Important Health Care Proxy Considerations

- (1) **Witness Requirements** – PHL section 2981(2)(c) and 14 NYCRR section 633.20(a)(2) contain special witness requirements for proxies executed by residents of OPWDD certified settings.

- (2) **Exception for artificial nutrition and hydration.** PHL section 2982(2) provides generally that the health care agent is to make decisions in accordance with the person's wishes, if known. If not known, decisions are to be made in accordance with the person's best interest.

  However, if the person's wishes regarding artificial nutrition and hydration are not known, the agent does not have the authority to make decisions regarding these matters. In such situations, consider using HCDA process.

Three Categories of FHCDA Potential Carve Outs

For individuals in hospitals, nursing homes or receiving hospice the FHCDA requires further inquiry by the attending practitioner (doctor, NP or PA) if:

(1) Person was transferred from an OPWDD operated or certified residential facility; or

(2) Attending practitioner has reason to believe that person has history of receiving I/DD services; or

(3) It reasonably appears to the attending practitioner that the person has I/DD.

PHL section 2994-b(3)

FHCDA Carve Outs

- Individuals in category # 1 – HCDA I/DD applies.
- For individuals in categories 2 and 3, we should check TABS to verify individual's service history or eligibility. HCDA applies if service history or diagnosis of ID. Includes DD if OPWDD eligibility has been confirmed. If not, hospitals may choose to use FHCDA.

Impact of FHCDA

- Revoked prior DNR Law
- Added DNR to category of withholding LST under HCDA

(1) No more “Medical Futility” criteria.

(2) No more physician-initiated DNR.

(3) No more “close friend.” Must use HCDA surrogate, which includes SDMC.

(4) Must meet HCDA criteria including extraordinary burden at the time the decision is being made.

(5) Must notify MHLS if person resides in OPWDD certified setting.

MOLST Approval

- As of January, 2011 OPWDD approved use of revised MOLST Form (DOH-5003)

- Completion of MOLST Checklist for persons with I/DD is **required** if MOLST is being used. Completed checklist should be attached and should match the signed MOLST.

Recent Developments

- eMOLST
- Amendments to PHL regarding Nurse Practitioners and Physician Assistants
  - Amends FHCDA to authorize attending NPs to perform functions of attending physicians – effective May 28, 2018.
  - Amends FHCDA to authorize PAs to perform functions of attending physicians (changes term to practitioners) – effective June 17, 2020.

**** HCDA for Individuals with I/DD has not been amended*. Attending and concurring medical determinations must be by physicians (step 4 of OPWDD checklist).**

Recent Developments

- Revised MOLST – dated August, 2020
  - Available on DOH website
  - Adds NP and PA as options (exception for individuals with I/DD under 1750-b: MOLST must be signed by a physician and not a NP or PA)
  - New language added to page 4

  Further MOLST revisions are currently being reviewed with DOH.

Recent Developments

- Amendments to Health Care Proxy Law (effective June 17, 2020)
  - Adds Nurse Practitioners (NP) and Physician Assistants (PA) as option instead of physicians for purposes of:
    - Acting as a witness to execution of HCP (must also meet employment/experience requirements in 633.20).
    - Making a determination as the attending of the principal's lack of capacity in order to empower the health care agent.
    - Providing the concurring opinion regarding lack of capacity in order to empower the agent, if the attending determines that lack of capacity is due to I/DD and the attending practitioner does not meet employment/experience requirements.

Recent Developments

- Providing the concurring opinion regarding lack of capacity in order to empower the health care agent for a decision to withhold or withdraw LST.
- When acting as the attending practitioner, confirming the principal's continued lack of capacity before complying with a health care agent's decision, other than those made at the time of the initial determination of incapacity.

Recent Developments

- Amendments to Health Care Proxy Law to give Physician Assistants same authority as NPs were effective on June 17, 2020.
- Conforming amendments to OPWDD regulation in 633.20 (adding NPs and PAs) are being developed.

Questions

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