HUMAN SERVICES

BUREAU OF GUARDIANSHIP SERVICES

Decision-Making for the Terminally Ill

Proposed Readoption with Amendments: N.J.A.C. 10:48B

Authorized By: Elizabeth Connolly, Acting Commissioner, Department of Human Services.

Authority: N.J.S.A. 26:2H-53 et seq., and 26:6A-1 et seq.

Calendar Reference: See Summary below for explanation of exception to calendar requirement.

Proposal Number: PRN 2016-112.

Submit comments by September 16, 2016, to:

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The agency proposal follows:

Summary

N.J.A.C. 10:48B, Decision-Making for the Terminally Ill, was scheduled to expire on June 15, 2016, pursuant to N.J.S.A. 52:14B-5.1. As the Department of Human Services (Department) has filed this notice prior to that date, the expiration date is extended 180 days to December 12, 2016, pursuant to N.J.S.A. 52:14B-5.1.c(2). The chapter provides specific ethical considerations related to decisions to continue or discontinue medical treatment for a terminally ill person with intellectual or developmental disabilities (ID/DD). Further, the chapter sets forth specific guidelines for the Bureau of Guardianship Services (BGS) when making these complex decisions on behalf of a person served. The Department has determined that the chapter should be readopted with technical amendments. The chapter remains relevant and effective, however, updates are necessary to remove outdated language, clarify specific provisions, and add references to new legislation.

The chapter contains eight subchapters as follows:

N.J.A.C. 10:48B-1, General Principles, addresses specific ethical considerations for the population served. Information regarding access to quality palliative care and a reference to the knowledge base of recognized ethics committee members.

N.J.A.C. 10:48B-2, Definitions, contains definitions for relevant terms contained in the chapter. The proposed amendments recognize that advanced practice nurses, as well as licensed physicians, may have primary responsibility for treatment and care of individuals covered by this chapter. Throughout the chapter, the term “attending physician” has been replaced with “treating practitioner.” The Department is also adding a definition of Physician’s Order for Life Sustaining Treatment (POLST). This

proposed amendment implements the requirements P.L. 2011, c. 145. The definition of "hospice" changes the name of the Department of Health and Senior Services to the Department of Health, pursuant to P.L. 2012, c. 17.

N.J.A.C. 10:48B-3, Ethics Committees, describes the requirements of recognized ethics committees that may be used as consultation for end-of-life decision-making for terminally ill individuals with ID/DD. Proposed amendments to N.J.A.C. 10:48B-3.1 specify that no fewer than three committee members must participate in an ethics consultation.

N.J.A.C. 10:48B-4, Decision-Making Capacity, outlines the process of determining whether a terminally ill person has the capacity to make end-of-life decisions. Further it explains the role of the attending medical practitioner in making this determination.

N.J.A.C. 10:48B-5, Individuals with Capacity to Make Medical Decisions, provides clarification that a person with capacity can independently make end-of-life decisions.

N.J.A.C. 10:48B-6, Individuals Without Capacity to Make Medical Treatment Decisions for whom BGS is Not Providing Guardianship Services. This subchapter provides guidelines for end-of-life decision-making when a surrogate decision-maker, other than BGS, is in place or is required.

N.J.A.C. 10:48B-7, Individuals Without Capacity to Make Medical Treatment Decisions for whom BGS is Providing Guardianship. This subchapter provides specific guidelines to the Bureau of Guardianship Services when making end-of-life decisions. The subchapter further describes the role of ethics committees and the procedures for

rendering the decision. Proposed amendments specify that immediate family members and/or Disability Rights New Jersey (DRNJ) may object to end-of-life decisions. "Interested parties" is replaced with "immediate family" in N.J.A.C. 10:48B-7.4 and 7.5. This change is intended to limit who may/may not object to an end-of-life decision. The term interested parties was too broad, creating a situation that permitted potentially uninvolved people to object to decisions about end-of-life care. Allowing any interested party to object could potentially delay an imminent and critical decision and is not seen to be in the best interest of the person served. Using the term immediate family members will allow for better protections for the person served while affording family an opportunity to object to the decision based on their knowledge of and relationship with the person. The proposed amendments remove a reference to the Public Advocate as that office no longer exists.

N.J.A.C. 10:48B-8 Palliative care, describes types of palliative care and specific requirements that may exist.

As the Department has provided a 60-day comment period on this notice of proposal, this notice is excepted from the rulemaking calendar requirement pursuant to N.J.A.C. 1:30-3.3(a)5.

Social Impact

Society has an interest in ensuring the soundness of the healthcare decision-making process, which includes both protecting vulnerable individuals from potential abuse or neglect and facilitating the exercise of informed and voluntary individual choice. The issue of providing medical intervention to individuals with developmental disabilities and terminal illnesses is complex. The rules proposed for readoption with

amendments will help to assure a system to protect the rights of those individuals so that they receive the highest quality of end-of-life care. The rules proposed for readoption with amendments outline the role of the Department when the Bureau of Guardianship Services is involved in that process.

The rules proposed for readoption with amendments emphasize the special ethical considerations necessary when making a decision to withhold or withdraw care and provide a system that protects individual rights, autonomy, and access to medical care including palliative care.

Economic Impact

The rules proposed for readoption with amendments will not have an economic impact.

Federal Standards Statement

The rules proposed for readoption with amendments governing decision-making for individuals with terminal illnesses contain requirements that do not exceed those imposed by Federal law or regulation. The rules proposed for readoption with amendments are in compliance with the New Jersey Advance Directives for Health Care Act (N.J.S.A. 26:2H-53 et seq.), the Federal Patient Self-Determination Act (42 U.S.C. § 1395 cc (a)), the New Jersey Declaration of Death Act (N.J.S.A. 26:6A-1 et seq.) and the New Jersey POLST (N.J.S.A. 26:2H-129 (P.L. 2011, c. 145)).

The Department has reviewed the applicable Federal statute, the Federal Patient Self-Determination Act (42 U.S.C. § 1395 cc (a)), and has determined that the rules proposed for readoption with amendments do not exceed the Federal requirements.

Jobs Impact

The rules proposed for readoption with amendments governing decision-making for individuals with terminal illness will not generate jobs or cause any jobs to be lost.

Agriculture Industry Impact

The rules proposed for readoption with amendments will have no impact on agriculture in the State of New Jersey.

Regulatory Flexibility Statement

A regulatory flexibility analysis is not required because the rules proposed for readoption with amendments do not impose reporting, recordkeeping, or other compliance requirements upon small businesses, as defined under the Regulatory Flexibility Act, N.J.S.A. 52:14B-16 et seq. Since the rules proposed for readoption with amendments apply only to individuals served by the Division, it will not have any effect on small businesses or private industry in general.

Housing Affordability Impact Analysis

The rules proposed for readoption with amendments will have an insignificant impact on the affordability of housing in New Jersey and there is an extreme unlikelihood that the rules would evoke a change in the average costs associated with housing because the rules concern decision-making for the terminally ill pertaining to life sustaining medical treatment.

Smart Growth Development Impact Analysis

The rules proposed for readoption with amendments will have an insignificant impact on smart growth and there is an extreme unlikelihood that the amendments would evoke a change in housing production in Planning Areas 1 or 2, or within designated centers, under the State Development and Redevelopment Plan in New

Jersey because the rules concern decision-making for the terminally ill pertaining to life sustaining medical treatment.

Full text of the rules proposed for readoption may be found in the New Jersey Administrative Code at N.J.A.C. 10:48B.

Full text of the proposed amendments follows (additions indicated in boldface **thus**; deletions indicated in brackets [thus]):

SUBCHAPTER 2. DEFINITIONS

10:48B-2.1 Definitions

The following words and terms, as used in this chapter, shall have the following meanings, unless the context clearly indicates otherwise:

…

[“Attending physician” means the physician selected by, or assigned to, the individual who has primary responsibility for the treatment and care of the individual.]

…

"Hospice" means a program, which is licensed by the New Jersey Department of Health [and Senior Services] to provide palliative services to terminally ill individuals in the individual's home or place of residence, including medical, nursing, social work, volunteer**,** and counseling services.

...

“Medical practitioner” means a person who is certified as an advanced practice nurse (APN) pursuant to N.J.S.A. 45:11-45 et seq., or a physician

licensed to practice medicine and surgery pursuant to Chapter 9 of Title 45 of the New Jersey Revised Statutes.

…

"Practitioners Order for Life Sustaining Treatment (POLST)" means a form of standardized medical order signed by a physician or advanced practice nurse that comports with New Jersey State laws and rules.

…

"Terminally ill individual" means an individual receiving services from the Division, who is under medical care and has reached the terminal stage of an irreversibly fatal illness, disease**,** or condition and the prognosis of the [attending physician] **treating practitioner** and at least one other physician asserts that the medical prognosis indicates a life expectancy of one year or less if the irreversibly fatal illness, disease**,** or condition continues on its normal course of progression, based upon reasonable medical certainty.

"Treating practitioner" means the medical practitioner selected by, or assigned to, the individual who has primary responsibility for the treatment and care of the individual.

SUBCHAPTER 3. ETHICS COMMITTEES

10:48B-3.1 Recognition of Ethics Committees

(a) The Assistant Commissioner or his or her designee shall recognize acute care hospital Ethics Committees and standing Ethics Committees to be independent of the

Division of Developmental Disabilities that shall be available for consultation to BGS whenever end-of-life decision-making issues arise.

1. An Ethics Committee, other than an acute care hospital Ethics Committee, shall assure to the Division the following:

i. (No change.)

ii. The ability to be available for case consultation in a prompt and expeditious manner proportionate to the urgency of the situation[. An absolute minimum of three members of the Ethics Committee must be involved to provide consultation for any case regardless of the degree of urgency thereof]; and

iii. (No change.)

2. (No change.)

(b) (No change.)

(c) [Each Ethics Committee] **A recognized ethics committee, whether it is an acute care hospital committee or otherwise recognized committee,** shall include a [membership of no less than five individuals] **pool of membership** optimally drawn from different disciplines[. Ideally the membership should include]**, such as the following**:

1.-8. (No change.)

(d) An absolute minimum of three of the committee members must participate in any ethics consultation.

SUBCHAPTER 4. DECISION-MAKING CAPACITY

10:48B-4.1 Determination of terminally ill individual's capacity regarding either Do Not Resuscitate (DNR) orders or the withholding or withdrawing of life-sustaining medical treatment (LSMT)

(a) It is the [attending physician's] **treating practitioner's** role to recommend a course of treatment for a terminally ill individual or an individual in a permanently unconscious state, including a Do Not Resuscitate (DNR) Order and/or the initiation, withholding**,** or withdrawing of life sustaining medical treatment (LSMT). In some instances, the [attending physician] **treating practitioner** may recommend a DNR order when the act of cardiopulmonary resuscitation is contraindicated due to the medical condition and/or age of the individual and could cause more physical harm than benefit.

(b) To the extent possible, Division staff shall provide to the [attending physician] **treating practitioner** any information or records pertinent to the issue of whether a terminally ill individual may or may not have the capacity to make medical treatment decisions, including documents such as a previous adjudication of incapacity or a determination [by the Chief Executive Officer (CEO) of a developmental center or Regional Administrator of a Division community services office] that the individual has capacity to make medical treatment decisions.

(c) If the [attending physician] **treating practitioner** recommends a DNR Order or the initiation, withdrawal**,** or withholding of LSMT, the [physician] **treating practitioner** must determine whether the individual has the capacity to make these medical treatment decisions. In some instances**,** the individual may not have the capacity to make major medical decisions, but may have the capacity to express some preferences about treatment options in the face of a terminal illness. The [attending

physician] **treating practitioner** should make an effort to determine the preferences of the individual, and these should be considered in the development of the final treatment plan. If an individual who lacks decision-making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate measures utilized to sustain life be provided, that wish shall take precedence over any contrary recommendation or determination.

(d) The [attending physician] **treating practitioner** may consider information supplied by the Division staff**,** BGS, or other interested persons to determine whether the terminally ill individual has the capacity to make medical decisions.

(e) The [attending physician] **treating practitioner** shall determine whether the patient lacks capacity to make a particular health care decision. The determinations shall be stated in writing, shall include the [attending physician's] **treating practitioner's** opinion concerning the nature**,** cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

(f) The [attending physician's] **treating practitioner's** determination of a lack of decision-making capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's record in the same manner as that of the [attending physician] **treating practitioner**. Confirmation of a lack of decision-making capacity is not required when the patient's lack of decision-making capacity is clearly apparent, and the [attending physician] **treating practitioner** and the legal guardian or health care representative agree that confirmation is unnecessary.

(g) If the [attending physician] **treating practitioner** or the confirming physician determines that a patient lacks decision-making capacity because of a mental or psychological impairment or a developmental disability, and neither the [attending physician] **treating practitioner** or the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decision-making capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's record in the same manner as that of the [attending physician] **treating practitioner**.

(h) The [attending physician] **treating practitioner** will notify the individual, the guardian**,** or the immediate family when the individual is determined to lack capacity to make a particular healthcare decision, the right to appeal this decision**,** and how to appeal.

SUBCHAPTER 5. INDIVIDUALS WITH CAPACITY TO MAKE MEDICAL DECISIONS

10:48B-5.1 Individuals with capacity to make medical decisions

If the [attending physician] **treating practitioner** has determined that a terminally ill individual has capacity to make informed major medical decisions on his or her own behalf, the individual shall make decisions regarding any proposed DNR Order and/or the withholding or withdrawing of LSMT.

SUBCHAPTER 6. INDIVIDUALS WITHOUT CAPACITY TO MAKE MEDICAL TREATMENT DECISIONS FOR WHOM BGS IS NOT PROVIDING GUARDIANSHIP SERVICES

10:48B-6.1 Individuals without capacity to make medical treatment decisions for whom BGS is not providing guardianship services

(a) If the [attending physician] **treating practitioner** has determined that a terminally ill individual or an individual in a permanently unconscious state, not receiving guardianship services from BGS, lacks the capacity to make major medical decisions, decision-making in regard to medical treatment shall proceed according to the following guidelines:

1. If the individual has a guardian other than BGS and is in a healthcare facility operated or funded by the Division, a DNR Order or an order for the withholding or withdrawing of LSMT may be issued upon the recommendation of the [attending physician] **treating practitioner** and with the consent of the private guardian. An Ethics Committee review, independent of the healthcare facility, can occur if requested by the [attending physician] **treating practitioner**, the legal guardian**,** or an interested party. The head of service of the Division component responsible for the individual, or his or her designee, shall provide written notice of the entry of the order to Disabilities Rights New Jersey (DRNJ) no later than the next business day;

2.-3. (No change.)

SUBCHAPTER 7. INDIVIDUALS WITHOUT CAPACITY TO MAKE MEDICAL TREATMENT DECISIONS FOR WHOM BGS IS PROVIDING GUARDIANSHIP **SERVICES**

10:48B-7.1 Individuals without capacity to make medical treatment decisions for whom BGS is providing guardianship **services**

If the [attending physician] **treating practitioner** has determined that a terminally ill individual or an individual in a permanently unconscious state for whom BGS is providing guardianship lacks the capacity to make medical decisions, and the [physician] **treating practitioner** is recommending the withholding or withdrawing of LSMT, the recommendation shall be referred to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

10:48B-7.2 Role and functions of Ethics Committees

The Chief of BGS or his or her designee shall solicit consultation from a recognized Ethics Committee whenever consent for withholding or withdrawing LSMT is being requested by the [attending physician] **treating practitioner**. The Ethics Committee shall meet as soon as possible depending upon the urgency of the situation.

10:48B-7.3 Withholding or withdrawing life-sustaining medical treatment (LSMT) for individuals for whom BGS is providing guardianship services

(a) The following procedures shall be followed:

1. When a recommendation to authorize the withholding or withdrawal of LSMT is received by staff of BGS, the recommendation shall be referred to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

i. In preparation for presentation of a recommendation for withholding or withdrawing LSMT to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, the Chief of BGS or his or her designee shall:

(1) Request a search of the individual's records to determine whether or not an advance directive **or POLST** exists;

(2) Obtain a description in writing from the [attending physician] **treating practitioner** of the diagnosis and prognosis of the individual, which substantiates the reasonableness of withholding or withdrawing potentially LSMT based upon the finding that such treatment would be more burdensome than beneficial, and contrary to the individual's best interest;

(A) The [attending physician] **treating practitioner** will include in the written description specific treatment recommendations for the individual.

(3)-(4) (No change.)

ii. (No change.)

iii. When considering a request to withhold or withdraw potentially LSMT, the members of the Ethics Committee shall consider:

(1) The recommendation of the [attending physician] **treating practitioner**, including the diagnosis, prognosis**,** and medical treatment plan for the individual;

(2)–(9) (No change.)

iv.-vi. (No change.)

10:48B-7.4 Procedures for rendering decision

(a) (No change.)

(b) If DRNJ does not participate in the Ethics Committee meeting and the Ethics Committee recommends withholding or withdrawing LSMT, and the Chief of BGS or his or her designee concurs with the recommendation, the Chief or his or her designee shall prepare a certification outlining the following:

1. (No change.)

2. The request of the [attending physician] **treating practitioner**, including a diagnosis and prognosis and a medical treatment plan;

3.-7. (No change.)

8. The wishes of the individual in an advance directive **or POLST**, if one exists;

9.-10. (No change.)

(c) (No change.)

(d) If the Chief of BGS or his or her designee disagrees with, or has questions about, a recommendation of the Ethics Committee to withhold or withdraw potentially LSMT, he or she shall request a second review by the Ethics Committee in order to discuss the issues in question. If, after the second review, the Chief of BGS or his or her designee makes the decision not to consent to the request to withhold or withdraw LSMT, the order shall not be written. The Chief of BGS or his or her designee shall state in writing the reasons why consent has been denied. Copies of this statement

shall be provided to the [attending physician] **treating practitioner**, the Ethics Committee**,** and DRNJ.

(e) (No change.)

(f) In the event [an interested party] **immediate family**[, including the Public Advocate] and/or DRNJ objects to the decision of the Chief of BGS or his or her designee to withhold or withdraw LSMT, the decision will not be implemented without a court order.

10:48B-7.5 Do Not Resuscitate (DNR) Orders for individuals receiving BGS services

(a) The following procedures shall be followed when a recommendation has been made by the [attending physician] **treating practitioner** to execute a DNR Order for an individual for whom BGS is providing guardianship services:

1. The [attending physician] **treating practitioner** will submit a written recommendation for a DNR Order indicating the diagnosis and prognosis of the individual and the benefit or not if Cardiopulmonary Resuscitation (CPR) is instituted. If the individual is not terminally ill or permanently unconscious and the attending physician is recommending that CPR is medically contraindicated for the individual, the attending physician will specify in the written recommendation the reasons CPR is contraindicated.

2. (No change.)

3. A second treating physician will indicate in writing his or her concurrence with the [attending physician's] **treating practitioner's** recommendation for a DNR Order.

4.-5. (No change.)

6. If the Chief of BGS**,** or his or her designee concurs with the recommendation for a DNR Order, the Chief or his or her designee shall prepare a certification based upon the following:

i. The recommendation of the [attending physician] **treating practitioner**, including a diagnosis, prognosis**,** and a medical treatment plan;

ii.-vii. (No change.)

7. Once the certification has been completed, the Chief of BGS or his or her designee shall communicate consent to the DNR Order to the [attending physician] **treating practitioner** and provide DRNJ with a copy of the certification no later than the next business day.

8. If an emergent request for a DNR Order is made by the [attending physician] **treating practitioner** and the Chief of BGS, or his or her designee, agrees with the request and concurs that the request meets the requirements of this chapter, consent will be given to the [physician] **treating practitioner** to enter a DNR order.

9. (No change.)

(b) (No change.)

(c) In the event an [interested party, including the Public Advocate] **immediate family member** and/or DRNJ, objects to the decision of the Chief of BGS or his or her designee to consent to **a** DNR Order, the decision will not be implemented without a court order.