HUMAN SERVICES

(a)

BUREAU OF GUARDIANSHIP SERVICES

Decision-Making for the Terminally Ill

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

Proposed: July 18, 2016, at 48 N.J.R. 1409(a).
Adopted: November 4, 2016, by Elizabeth Connolly, Acting Commissioner, Department of Human Services.
Filed: November 29, 2016, as R.2017 d.003, **without change**.
Authority: N.J.S.A. 26:2H-53 et seq., and 26:6A-1 et seq.
Effective Dates: November 29, 2016, Readoption; January 3, 2017, Amendments.
Expiration Date: November 29, 2023.

Summary of Public Comment and Agency Response:

The agency received one comment from Disability Rights, New Jersey.

COMMENT: Disability Rights New Jersey (DRNJ) supports the changes proposed to N.J.A.C. 10:48B with one caution. N.J.A.C. 10:48B-7.5(c) proposes to substitute "immediate family member" for "interested party" when enumerating those with standing to object to the decision of the Bureau. The term "interested party" derives from the New Jersey Supreme court's decision in *In re Jobes*, one of a series of cases establishing guidelines for the termination of life sustaining medical treatment. DRNJ encourages the Bureau to liberally interpret "immediate family" to respect the concerns of someone actively involved with the individual. DRNJ notes that N.J.A.C 10:48B-2.1 has an expansive definition of "immediate family" that closely approximates the intention of the court in *Jobes*.

RESPONSE: Thank you for providing comments to the proposed amendments to N.J.A.C. 10:48B on behalf of DRNJ. Your recommendations have been reviewed and we agree with DRNJ's caution to interpret "immediate family member" liberally. As noted, NJ.A.C. 10:48B-2.1 includes an expansive definition of immediate family member which is consistent with the intentions of the court in *Jobes*. The definition and intent remain unchanged in the proposed version of N.J.A.C 10:48B.

Federal Standards Statement

. The rules readopted 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 readopted 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 Individual Self-Determination Act (42 U.S.C. § 1395cc (a)), the New Jersey Declaration of Death Act (N.J.S.A. 26:6A-1 et seq.) and the NJ POLST (N.J.S.A. 26:2H-129, P.L. 2011, c. 145).

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

Full text of the readopted rules can be found in the New Jersey Administrative Code at N.J.A.C. 10:48B.

Full text of the adopted amendments follows:

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:

. . .

"Hospice" means a program, which is licensed by the New Jersey Department of Health 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 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; and

iii. (No change.)

2. (No change.)

(b) (No change.)

(c) A recognized ethics committee, whether it is an acute care hospital committee or otherwise recognized committee, shall include a pool of membership optimally drawn from different disciplines, 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 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 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 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 that the individual has capacity to make medical treatment decisions.

(c) If the treating practitioner recommends a DNR Order or the initiation, withdrawal, or withholding of LSMT, the 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 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 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 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 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 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 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 treating practitioner and the legal guardian or health care representative agree that confirmation is unnecessary.

(g) If the 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 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 treating practitioner.

(h) The 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 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 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 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 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 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 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 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 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 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 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 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 treating practitioner, the Ethics Committee, and DRNJ.

(e) (No change.)

(f) In the event immediate family 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 treating practitioner to execute a DNR Order for an individual for whom BGS is providing guardianship services:

1. The 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 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 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 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 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 treating practitioner to enter a DNR order.

9. (No change.)

(b) (No change.)

(c) In the event an 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.

(a)

DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES

CHILDREN AND FAMILIES

DIVISION OF THE CHILDREN'S SYSTEM OF CARE

Psychiatric Residential Treatment Facility Services for Individuals Under Age 21

Readoption with Amendments: N.J.A.C. 10:75

Proposed: July 18, 2016, at 48 N.J.R. 1421(a).

Adopted: October 26, 2016, by Elizabeth Connolly, Acting Commissioner, Department of Human Services and September 26, 2016, by Allison Blake, Commissioner, Department of Children and Families.

Filed: November 30, 2016, as R.2017 d.004, **without change**.

Authority: N.J.S.A. 9:3A-7, 30:4D-1 et seq., and 30:4J-8 et seq.

Agency Control Number: 16-A-03.

Effective Dates: November 30, 2016, Readoption; January 3, 2017, Amendments.

Expiration Date: November 30, 2023.

Summary of Public Comment and Agency Response:

No comments were received.

Federal Standards Statement

Section 1902(a)(9)(A) of the Social Security Act (42 U.S.C. § 1396a) requires the state health agency or other state medical agency to establish and maintain health standards for private and public institutions in which beneficiaries of medical assistance, under the State Plan, receive care or services. The Social Security Act, at section 1903(g), requires the Division to establish and maintain an effective program to review the utilization of services in inpatient settings. (See also 42 CFR 456.480 through 456.482). Section 1905 of the Social Security Act (42 U.S.C. § 1396d) lists and defines the services that may be covered under the State medical assistance program. Psychiatric residential treatment facilities conform to the definition of an inpatient setting as set forth at Section 1905(h). Regulations at 42 CFR 440.160 and 441.150 through 441.182 define inpatient psychiatric services for individuals under age 21 and describe the requirements and limits of such services. Regulations at 42 CFR 483.350 through 483.376 provide conditions of participation related to the use of restraints and seclusion, including procedural, reporting, and training mandates as imposed by the Children's Health Act of 2000 (Pub. L. 106-310), when providing mental health services to individuals under the age of 21 in psychiatric residential treatment facilities.

Section 2101 of the Social Security Act (42 U.S.C. § 1397aa) provides funds to a state to administer a program providing a State-operated children's health insurance program for targeted, low-income children.

Within these general guidelines, the Federal laws and regulations anticipate that a state will promulgate regulations that define the scope of service, and any limitations applied to the services. The Departments have reviewed the Federal legal and regulatory requirements and have determined the rules proposed for readoption with amendments do not exceed Federal standards.

Therefore, a Federal standards analysis is not required.

Full text of the readopted rules can be found in the New Jersey Administrative Code at N.J.A.C. 10:75.

Full text of the adopted amendments follows:

SUBCHAPTER 1. GENERAL PROVISIONS

10:75-1.1 Purpose and scope

(a) This chapter outlines the policies and procedures relevant to the provision of psychiatric residential treatment facility services to individuals under age 21 enrolled in Medicaid/NJ FamilyCare–Plan A. The rules of this chapter also apply to children/youth/young adults