# STATE OF NEW YORK

890

2017-2018 Regular Sessions

# IN ASSEMBLY

January 9, 2017

Introduced by M. of A. GUNTHER, GOTTFRIED, BRONSON -- read once and referred to the Committee on Judiciary

AN ACT to amend the surrogate's court procedure act, in relation to making technical and coordinating amendments and other improvements regarding health care decisions for persons with developmental disabilities

**The People of the State of New York, represented in Senate and Assembly, do enact as follows:**

Section 1. Section 1750-b of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1750-b. Health care decisions for persons [~~who are intellectually disabled~~] **with developmental disabilities**

1. Scope of authority. **As used in this section, the terms "developmental disability" and "developmentally disabled" shall have the meaning set forth in subdivision twenty-two of section 1.03 of the mental hygiene law.** Unless specifically prohibited by the court after consideration of the determination, if any, regarding a person [~~who is intellectually disabled's~~] **with a developmental disability'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 person [~~who is intellectually disabled~~] **with a developmental disability** 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**, intubation and/or mechanical ventilation** and nutrition and hydration provided by means of medical treatment, which is **or would be**

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

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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 person [~~who is intellectually disabled~~] **with a developmental disability** 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 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~~] **an** 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 the office for people with 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~~] **justice center for the protection of people with special needs, as established by article twenty of the executive law**.

(b) Regulations establishing the prioritized list of qualified family members required by paragraph (a) of this subdivision shall be developed by the commissioner of the office for people with developmental disabilities in conjunction with parents, advocates and family members of persons [~~who are intellectually disabled~~] **with developmental disabilities**. 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 for people with 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.

**(d) A patient subject to this section who is found by the attending physician to have capacity to make his or her own health care decisions, pursuant to paragraph (a) of subdivision four of this section, upon notice to the chief executive officer of a residential facility operated, licensed or authorized by the office for people with developmental disabilities, in which facility the patient resides or from which he or she was transferred, and the mental hygiene legal service, may make his or her own decisions relating to life-sustaining treatment.**

**(e) A patient subject to this section who has a valid health care proxy at the time of a health care decision, including a decision involving life-sustaining treatment, shall have such decisions made in accordance with article twenty-nine-C of the public health law. If for any reason the agent or an alternate agent is not reasonably available, willing and competent to serve and the patient is otherwise eligible to have a decision as to life-sustaining treatment made pursuant to this section, any guardian or person or entity entitled to exercise the authority of a guardian under paragraph (a) of this subdivision may make such decision.**

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 person [~~who is intellectually disabled~~] **with a developmental disability** and, when reasonably known or ascertainable with reasonable diligence, on [~~the person who is intellectually disabled's~~] **such person's** wishes, including moral and religious beliefs.

(b) An assessment of the person [~~who is intellectually disabled's~~] **with a developmental disability's** best interests shall include consideration of:

(i) the dignity and uniqueness of every person;

(ii) the preservation, improvement or restoration of the [~~person who is intellectually disabled's~~] **person's** health;

(iii) the relief of the [~~person who is intellectually disabled's~~] **person's** suffering by means of palliative care and pain management;

(iv) the unique nature of [~~artificially provided~~] nutrition or hydration **provided by means of medical treatment**, and the effect it may have on the person [~~who is intellectually disabled~~]; 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 [~~who are intellectually disabled~~] **with developmental disabilities** are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to persons without [~~an intellectual disability or a developmental disability~~] **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 person [~~who~~

~~is intellectually disabled's~~] **with a developmental disability'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~~] **initiates** a decision to withdraw or withhold life-sustaining treatment from a person [~~who is intellectually disabled~~] **with a developmental disability**:

(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 person [~~who is intellectually disabled~~] **with a developmental disability** lacks capacity to make health care decisions. The determination thereof shall be included in the [~~person who is intellectually disabled's~~] **person's** medical record, and shall contain such attending physician's opinion regarding the cause and nature of the [~~person who is intellectually disabled's~~] **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 [~~person who is intellectually disabled's~~] **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~~] **regional** 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 for people with developmental disabilities, or (iii) have been approved by the commissioner of the office for people with 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 disability~~] **people with developmental disabilities**. A record of such consultation shall be included in the [~~person who is intellectually disabled's~~] **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 person [~~who is intellectually disabled's~~] **with a developmental disability's** chart that:

(i) the person [~~who is intellectually disabled~~] 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~~] **which shall mean an illness or injury from which there is no recovery, and which can reasonably be expected to cause death within one year**; or

B. permanent unconsciousness; or

C. a medical condition other than such person's [~~intellectual~~] **developmental** disability which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and

(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~~] **developmental** disability; and

B. the expected outcome of the life-sustaining treatment, notwithstanding such person's [~~intellectual~~] **developmental** 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 person [~~who is intellectually disabled's~~] **with a developmental disability'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 person [~~who is intellectually disabled's~~] **with a developmental disability's** medical chart, and shall either:

(i) promptly issue an order to withhold or withdraw life-sustaining treatment from the person [~~who is intellectually disabled~~], 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 person [~~who is intellectually disabled~~] **with a developmental disability**, 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 for people with developmental disabilities, or

C. have been approved by the commissioner of the office for people with 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 disability~~] **developmental disabilities**. A record of such consultation shall be included in the [~~person who is intellectually disabled's~~] **person's** medical record;

(ii) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office for people with developmental disabilities, the chief executive officer of the agency or organization operating such facility and the mental hygiene legal

service. Notification to the facility director and the mental hygiene legal service shall not delay issuance of an order not to resuscitate; and

(iii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

(f) For a patient residing in a facility operated, licensed or authorized by the office for people with developmental disabilities as to whom an order not to resuscitate has been entered, the attending physician shall review whether the order is still appropriate at such times and in such manner as is prescribed by subdivision four of section twenty-nine hundred ninety-four-dd of the public health law.

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 person [~~who is intellectually disabled~~] with a developmental disability, in the event of an objection to that decision at any time by:

(i) the person [~~who is intellectually disabled~~] 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 person [~~who is intellectually disabled~~]; 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 person [~~who is intellectually disabled~~], 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 for people with developmental disabilities, 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 for people with developmental disabilities, or his or her designee.

Notwithstanding the foregoing, in cases where the attending physician has notified the chief executive officer of an agency and the mental hygiene legal service of the entry of an order not to resuscitate pursuant to subparagraph (ii) of paragraph (e) of subdivision four of this section, and if such notice includes either the physician's statement of the diagnostic and basis for the medical determination in support of the prognostic order or an excerpt from the patient's medical record that is sufficient to support such determination, an order not to resuscitate shall not be stayed by an objection by the persons described in subparagraph (v) or (vi) of this paragraph unless the objection is accompanied by (A) a written statement by the objecting party setting forth a basis for asserting that a standard in this article for entering such an order has not been met; and (B) if the basis relates to the failure to meet medical criteria in this article for the issuance of the order, a written statement by a health or social services practitioner, as defined in

subdivision seventeen of section twenty-nine hundred ninety-four-a of the public health law setting forth the professional's opinion, based on his or her review of the aforementioned statement or medical record excerpt and consultation with the patient's attending physician, that the medical criteria in this article for entering such order have not been met.

(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 person [~~who is intellectually disabled's~~] with a developmental disability'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 objection shall be referred to [~~a dispute mediation system, established pursuant to section two thousand nine hundred seventy-two~~] an ethics review committee, established pursuant to section twenty-nine hundred ninety-four-m of the public health law or similar entity for mediating disputes in a hospice, such as a patient's advocate's office[~~,~~] or 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~~] may 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 of the office for people with developmental disabilities 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 person [~~who is intellectually disabled~~] with a developmental disability, 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 person [~~who is intellectually disabled~~]

with a developmental disability, 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 person [~~who is intellectually disabled~~] 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 person [~~who is intellectually disabled~~] with a developmental disability, 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 person [~~who is intellectually disabled~~] 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 person [~~who is intellectually disabled~~] with a developmental disability, 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 person [~~who is intellectually disabled~~] 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.

§ 2. This act shall take effect on the ninetieth day after it shall have become a law.