

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:

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

4 § 1750-b. Health care decisions for persons [~~who are intellectually~~
5 ~~disabled~~] with developmental disabilities

6 1. Scope of authority. As used in this section, the terms "develop-
7 mental disability" and "developmentally disabled" shall have the meaning
8 set forth in subdivision twenty-two of section 1.03 of the mental
9 hygiene law. Unless specifically prohibited by the court after consider-
10 ation of the determination, if any, regarding a person [~~who is intellec-~~
11 ~~tually disabled's~~] with a developmental disability's capacity to make
12 health care decisions, which is required by section seventeen hundred
13 fifty of this article, the guardian of such person appointed pursuant to
14 section seventeen hundred fifty of this article shall have the authority
15 to make any and all health care decisions, as defined by subdivision six
16 of section twenty-nine hundred eighty of the public health law, on
17 behalf of the person [~~who is intellectually disabled~~] with a develop-
18 mental disability that such person could make if such person had capaci-
19 ty. Such decisions may include decisions to withhold or withdraw life-
20 sustaining treatment. For purposes of this section, "life-sustaining
21 treatment" means medical treatment, including cardiopulmonary resusci-
22 tation, intubation and/or mechanical ventilation and nutrition and
23 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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1 sustaining life functions and without which, according to reasonable
2 medical judgment, the patient will die within a relatively short time
3 period. Cardiopulmonary resuscitation is presumed to be life-sustaining
4 treatment without the necessity of a medical judgment by an attending
5 physician. The provisions of this article are not intended to permit or
6 promote suicide, assisted suicide or euthanasia; accordingly, nothing in
7 this section shall be construed to permit a guardian to consent to any
8 act or omission to which the person ~~[who is intellectually disabled]~~
9 with a developmental disability could not consent if such person had
10 capacity.

11 (a) For the purposes of making a decision to withhold or withdraw
12 life-sustaining treatment pursuant to this section, in the case of a
13 person for whom no guardian has been appointed pursuant to section
14 seventeen hundred fifty or seventeen hundred fifty-a of this article, a
15 "guardian" shall also mean a family member of a person who ~~[(i) has~~
16 ~~intellectual disability, or (ii)]~~ has a developmental disability, as
17 defined in section 1.03 of the mental hygiene law, which ~~[(A) includes~~
18 ~~intellectual disability, or (B)]~~ results in ~~[a similar]~~ an impairment of
19 general intellectual functioning or adaptive behavior so that such
20 person is incapable of managing himself or herself, and/or his or her
21 affairs by reason of such developmental disability. Qualified family
22 members shall be included in a prioritized list of said family members
23 pursuant to regulations established by the commissioner of the office
24 for people with developmental disabilities. Such family members must
25 have a significant and ongoing involvement in a person's life so as to
26 have sufficient knowledge of their needs and, when reasonably known or
27 ascertainable, the person's wishes, including moral and religious
28 beliefs. In the case of a person who was a resident of the former
29 Willowbrook state school on March seventeenth, nineteen hundred seven-
30 ty-two and those individuals who were in community care status on that
31 date and subsequently returned to Willowbrook or a related facility, who
32 are fully represented by the consumer advisory board and who have no
33 guardians appointed pursuant to this article or have no qualified family
34 members to make such a decision, then a "guardian" shall also mean the
35 Willowbrook consumer advisory board. A decision of such family member or
36 the Willowbrook consumer advisory board to withhold or withdraw life-
37 sustaining treatment shall be subject to all of the protections, proce-
38 dures and safeguards which apply to the decision of a guardian to with-
39 hold or withdraw life-sustaining treatment pursuant to this section.

40 In the case of a person for whom no guardian has been appointed pursu-
41 ant to this article or for whom there is no qualified family member or
42 the Willowbrook consumer advisory board available to make such a deci-
43 sion, a "guardian" shall also mean, notwithstanding the definitions in
44 section 80.03 of the mental hygiene law, a surrogate decision-making
45 committee, as defined in article eighty of the mental hygiene law. All
46 declarations and procedures, including expedited procedures, to comply
47 with this section shall be established by regulations promulgated by the
48 ~~[commission on quality of care and advocacy for persons with disabili-~~
49 ~~ties]~~ justice center for the protection of people with special needs, as
50 established by article twenty of the executive law.

51 (b) Regulations establishing the prioritized list of qualified family
52 members required by paragraph (a) of this subdivision shall be developed
53 by the commissioner of the office for people with developmental disabil-
54 ities in conjunction with parents, advocates and family members of
55 persons ~~[who are intellectually disabled]~~ with developmental disabili-
56 ties. Regulations to implement the authority of the Willowbrook consumer

1 advisory board pursuant to paragraph (a) of this subdivision may be
2 promulgated by the commissioner of the office for people with develop-
3 mental disabilities with advice from the Willowbrook consumer advisory
4 board.

5 (c) Notwithstanding any provision of law to the contrary, the formal
6 determinations required pursuant to section seventeen hundred fifty of
7 this article shall only apply to guardians appointed pursuant to section
8 seventeen hundred fifty or seventeen hundred fifty-a of this article.

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

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

27 2. Decision-making standard. (a) The guardian shall base all advocacy
28 and health care decision-making solely and exclusively on the best
29 interests of the person [~~who is intellectually disabled~~] with a develop-
30 mental disability and, when reasonably known or ascertainable with
31 reasonable diligence, on [~~the person who is intellectually disabled's~~]
32 such person's wishes, including moral and religious beliefs.

33 (b) An assessment of the person [~~who is intellectually disabled's~~]
34 with a developmental disability's best interests shall include consider-
35 ation of:

- 36 (i) the dignity and uniqueness of every person;
37 (ii) the preservation, improvement or restoration of the [~~person who~~
38 ~~is intellectually disabled's~~] person's health;
39 (iii) the relief of the [~~person who is intellectually disabled's~~]
40 person's suffering by means of palliative care and pain management;
41 (iv) the unique nature of [~~artificially provided~~] nutrition or
42 hydration provided by means of medical treatment, and the effect it may
43 have on the person [~~who is intellectually disabled~~]; and
44 (v) the entire medical condition of the person.

45 (c) No health care decision shall be influenced in any way by:

- 46 (i) a presumption that persons [~~who are intellectually disabled~~] with
47 developmental disabilities are not entitled to the full and equal
48 rights, equal protection, respect, medical care and dignity afforded to
49 persons without [~~an intellectual disability or a developmental disabili-~~
50 ~~ty~~] developmental disabilities; or

51 (ii) financial considerations of the guardian, as such considerations
52 affect the guardian, a health care provider or any other party.

53 3. Right to receive information. Subject to the provisions of sections
54 33.13 and 33.16 of the mental hygiene law, the guardian shall have the
55 right to receive all medical information and medical and clinical
56 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

1 B. the expected outcome of the life-sustaining treatment, notwith-
2 standing such person's [~~intellectual~~] developmental disability; and
3 (iii) in the case of a decision to withdraw or withhold artificially
4 provided nutrition or hydration:

5 A. there is no reasonable hope of maintaining life; or

6 B. the artificially provided nutrition or hydration poses an extraor-
7 dinary burden.

8 (c) The guardian shall express a decision to withhold or withdraw
9 life-sustaining treatment either:

10 (i) in writing, dated and signed in the presence of one witness eigh-
11 teen years of age or older who shall sign the decision, and presented to
12 the attending physician, as defined in subdivision two of section twen-
13 ty-nine hundred eighty of the public health law; or

14 (ii) orally, to two persons eighteen years of age or older, at least
15 one of whom is the person [~~who is intellectually disabled's~~] with a
16 developmental disability's attending physician, as defined in subdivi-
17 sion two of section twenty-nine hundred eighty of the public health law.

18 (d) The attending physician, as defined in subdivision two of section
19 twenty-nine hundred eighty of the public health law, who is provided
20 with the decision of a guardian shall include the decision in the person
21 [~~who is intellectually disabled's~~] with a developmental disability's
22 medical chart, and shall either:

23 (i) promptly issue an order to withhold or withdraw life-sustaining
24 treatment from the person [~~who is intellectually disabled~~], and inform
25 the staff responsible for such person's care, if any, of the order; or

26 (ii) promptly object to such decision, in accordance with subdivision
27 five of this section.

28 (e) At least forty-eight hours prior to the implementation of a deci-
29 sion to withdraw life-sustaining treatment, or at the earliest possible
30 time prior to the implementation of a decision to withhold life-sustain-
31 ing treatment, the attending physician shall notify:

32 (i) the person [~~who is intellectually disabled~~] with a developmental
33 disability, except if the attending physician determines, in writing and
34 in consultation with another physician or a licensed psychologist, that,
35 to a reasonable degree of medical certainty, the person would suffer
36 immediate and severe injury from such notification. The attending physi-
37 cian who makes the confirmation, or the physician or licensed psychol-
38 ogist with whom the attending physician consults, shall:

39 A. be employed by a developmental disabilities services office named
40 in section 13.17 of the mental hygiene law or employed by the office for
41 people with developmental disabilities to provide treatment and care to
42 people with developmental disabilities, or

43 B. have been employed for a minimum of two years to render care and
44 service in a facility operated, licensed or authorized by the office for
45 people with developmental disabilities, or

46 C. have been approved by the commissioner of the office for people
47 with developmental disabilities in accordance with regulations promul-
48 gated by such commissioner. Such regulations shall require that a physi-
49 cian or licensed psychologist possess specialized training or three
50 years experience in treating [~~intellectual disability~~] developmental
51 disabilities. A record of such consultation shall be included in the
52 [~~person who is intellectually disabled's~~] person's medical record;

53 (ii) if the person is in or was transferred from a residential facili-
54 ty operated, licensed or authorized by the office for people with devel-
55 opmental disabilities, the chief executive officer of the agency or
56 organization operating such facility and the mental hygiene legal

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

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

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

13 5. Objection to health care decision. (a) Suspension. A health care
14 decision made pursuant to subdivision four of this section shall be
15 suspended, pending judicial review, except if the suspension would in
16 reasonable medical judgment be likely to result in the death of the
17 person [~~who is intellectually disabled~~] with a developmental disability,
18 in the event of an objection to that decision at any time by:

19 (i) the person [~~who is intellectually disabled~~] on whose behalf such
20 decision was made; or

21 (ii) a parent or adult sibling who either resides with or has main-
22 tained substantial and continuous contact with the person [~~who is intel-~~
23 ~~lectually disabled~~]; or

24 (iii) the attending physician, as defined in subdivision two of
25 section twenty-nine hundred eighty of the public health law; or

26 (iv) any other health care practitioner providing services to the
27 person [~~who is intellectually disabled~~], who is licensed pursuant to
28 article one hundred thirty-one, one hundred thirty-one-B, one hundred
29 thirty-two, one hundred thirty-three, one hundred thirty-six, one
30 hundred thirty-nine, one hundred forty-one, one hundred forty-three, one
31 hundred forty-four, one hundred fifty-three, one hundred fifty-four, one
32 hundred fifty-six, one hundred fifty-nine or one hundred sixty-four of
33 the education law; or

34 (v) the chief executive officer identified in subparagraph (ii) of
35 paragraph (e) of subdivision four of this section; or

36 (vi) if the person is in or was transferred from a residential facili-
37 ty or program operated, approved or licensed by the office for people
38 with developmental disabilities, the mental hygiene legal service; or

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

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

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

7 (b) Form of objection. Such objection shall occur orally or in writ-
8 ing.

9 (c) Notification. In the event of the suspension of a health care
10 decision pursuant to this subdivision, the objecting party shall prompt-
11 ly notify the guardian and the other parties identified in paragraph (a)
12 of this subdivision, and the attending physician shall record such
13 suspension in the person [~~who is intellectually disabled's~~] with a
14 developmental disability's medical chart.

15 (d) Dispute mediation. In the event of an objection pursuant to this
16 subdivision, at the request of the objecting party or person or entity
17 authorized to act as a guardian under this section, except a surrogate
18 decision making committee established pursuant to article eighty of the
19 mental hygiene law, such objection shall be referred to [~~a dispute medi-~~
20 ~~ation system, established pursuant to section two thousand nine hundred~~
21 ~~seventy-two~~] an ethics review committee, established pursuant to section
22 twenty-nine hundred ninety-four-m of the public health law or similar
23 entity for mediating disputes in a hospice, such as a patient's advo-
24 cate's office[, or hospital chaplain's office [~~or ethics committee~~], as
25 described in writing and adopted by the governing authority of such
26 hospice, for non-binding mediation. In the event that such dispute
27 cannot be resolved within seventy-two hours or no such mediation entity
28 exists or is reasonably available for mediation of a dispute, the
29 objection [~~shall~~] may proceed to judicial review pursuant to this subdi-
30 vision. The party requesting mediation shall provide notification to
31 those parties entitled to notice pursuant to paragraph (a) of this
32 subdivision.

33 6. Special proceeding authorized. The guardian, the attending physi-
34 cian, as defined in subdivision two of section twenty-nine hundred
35 eighty of the public health law, the chief executive officer identified
36 in subparagraph (ii) of paragraph (e) of subdivision four of this
37 section, the mental hygiene legal service (if the person is in or was
38 transferred from a residential facility or program operated, approved or
39 licensed by the office for people with developmental disabilities) or
40 the commissioner of the office for people with developmental disabili-
41 ties or his or her designee (if the person is not in and was not trans-
42 ferred from such a facility or program) may commence a special proceed-
43 ing in a court of competent jurisdiction with respect to any dispute
44 arising under this section, including objecting to the withdrawal or
45 withholding of life-sustaining treatment because such withdrawal or
46 withholding is not in accord with the criteria set forth in this
47 section.

48 7. Provider's obligations. (a) A health care provider shall comply
49 with the health care decisions made by a guardian in good faith pursuant
50 to this section, to the same extent as if such decisions had been made
51 by the person [~~who is intellectually disabled~~] with a developmental
52 disability, if such person had capacity.

53 (b) Notwithstanding paragraph (a) of this subdivision, nothing in this
54 section shall be construed to require a private hospital to honor a
55 guardian's health care decision that the hospital would not honor if the
56 decision had been made by the person [~~who is intellectually disabled~~]

1 with a developmental disability, if such person had capacity, because
2 the decision is contrary to a formally adopted written policy of the
3 hospital expressly based on religious beliefs or sincerely held moral
4 convictions central to the hospital's operating principles, and the
5 hospital would be permitted by law to refuse to honor the decision if
6 made by such person, provided:

7 (i) the hospital has informed the guardian of such policy prior to or
8 upon admission, if reasonably possible; and

9 (ii) the person [~~who is intellectually disabled~~] is transferred
10 promptly to another hospital that is reasonably accessible under the
11 circumstances and is willing to honor the guardian's decision. If the
12 guardian is unable or unwilling to arrange such a transfer, the hospi-
13 tal's refusal to honor the decision of the guardian shall constitute an
14 objection pursuant to subdivision five of this section.

15 (c) Notwithstanding paragraph (a) of this subdivision, nothing in this
16 section shall be construed to require an individual health care provider
17 to honor a guardian's health care decision that the individual would not
18 honor if the decision had been made by the person [~~who is intellectually~~
19 ~~disabled~~] with a developmental disability, if such person had capacity,
20 because the decision is contrary to the individual's religious beliefs
21 or sincerely held moral convictions, provided the individual health care
22 provider promptly informs the guardian and the facility, if any, of his
23 or her refusal to honor the guardian's decision. In such event, the
24 facility shall promptly transfer responsibility for the person [~~who is~~
25 ~~intellectually disabled~~] to another individual health care provider
26 willing to honor the guardian's decision. The individual health care
27 provider shall cooperate in facilitating such transfer of the patient.

28 (d) Notwithstanding the provisions of any other paragraph of this
29 subdivision, if a guardian directs the provision of life-sustaining
30 treatment, the denial of which in reasonable medical judgment would be
31 likely to result in the death of the person [~~who is intellectually disa-~~
32 ~~bled~~] with a developmental disability, a hospital or individual health
33 care provider that does not wish to provide such treatment shall none-
34 theless comply with the guardian's decision pending either transfer of
35 the person [~~who is intellectually disabled~~] to a willing hospital or
36 individual health care provider, or judicial review.

37 (e) Nothing in this section shall affect or diminish the authority of
38 a surrogate decision-making panel to render decisions regarding major
39 medical treatment pursuant to article eighty of the mental hygiene law.

40 8. Immunity. (a) Provider immunity. No health care provider or employ-
41 ee thereof shall be subjected to criminal or civil liability, or be
42 deemed to have engaged in unprofessional conduct, for honoring reason-
43 ably and in good faith a health care decision by a guardian, or for
44 other actions taken reasonably and in good faith pursuant to this
45 section.

46 (b) Guardian immunity. No guardian shall be subjected to criminal or
47 civil liability for making a health care decision reasonably and in good
48 faith pursuant to this section.

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