

STATE OF NEW YORK

8648

2025-2026 Regular Sessions

IN ASSEMBLY

May 22, 2025

Introduced by M. of A. LAVINE -- read once and referred to the Committee on Health

AN ACT to and the public health law and the surrogate's court procedure act, in relation to extending the family health care decisions act to health care decisions for patients with intellectual or developmental disabilities; and to repeal certain provisions of the surrogate's court procedure act relating thereto

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

1 Section 1. Subdivision 3 of section 2994-b of the public health law,
2 as amended by chapter 708 of the laws of 2019, the opening paragraph as
3 amended by chapter 40 of the laws of 2024, is amended to read as
4 follows:

5 3. Prior to seeking or relying upon a health care decision by a surro-
6 gate for a patient under this article, if [~~the attending practitioner~~
7 ~~has reason to believe that the patient has a history of receiving~~
8 ~~services for an intellectual or developmental disability; it reasonably~~
9 ~~appears to the attending practitioner that the patient has an intellec-~~
10 ~~tual or developmental disability; or]~~ the practitioner in a general
11 hospital has reason to believe that the patient has been temporarily
12 transferred from a mental hygiene facility operated or licensed by the
13 office of mental health [~~or the office for people with developmental~~
14 ~~disabilities, then such physician, nurse practitioner or physician~~
15 ~~assistant shall make reasonable efforts to determine whether paragraph~~
16 ~~(a), (b) or (c) of this subdivision is applicable:~~

17 ~~(a) If the patient has a guardian appointed by a court pursuant to~~
18 ~~article seventeen-A of the surrogate's court procedure act, health care~~
19 ~~decisions for the patient shall be governed by section seventeen hundred~~
20 ~~fifty b of the surrogate's court procedure act and not by this article.~~

21 ~~(b) If a patient does not have a guardian appointed by a court pursu-~~
22 ~~ant to article seventeen-A of the surrogate's court procedure act but~~

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

LBD13049-01-5

~~falls within the class of persons described in paragraph (a) of subdivision one of section seventeen hundred fifty-b of such act, decisions to withdraw or withhold life-sustaining treatment for the patient shall be governed by section seventeen hundred fifty-b of the surrogate's court procedure act and not by this article.~~

~~(c) If a health care decision for a patient cannot be made under paragraphs (a) or (b) of this subdivision, but]~~ and that consent for the decision may be provided pursuant to the mental hygiene law or regulations of the office of mental health ~~[or the office for people with developmental disabilities]~~, then the decision shall be governed by such statute or regulations and not by this article.

§ 2. Subdivision 1 and paragraph (a) of subdivision 4 of section 2994-c of the public health law, as added by chapter 8 of the laws of 2010, are amended to read as follows:

1. Presumption of capacity. For purposes of this article, every adult shall be presumed to have decision-making capacity unless:

(a) determined otherwise pursuant to this section or pursuant to court order[7]; or [unless]

(b) a guardian is authorized to decide about health care for the adult pursuant to article eighty-one of the mental hygiene law; or

(c) a guardian has been appointed for the adult pursuant to article seventeen-A of the surrogate's court procedure act.

(a) to the patient, where there is any indication of the patient's ability to comprehend the information, provided that such notice to a patient with an intellectual or developmental disability is governed by subdivision one of section twenty-nine hundred ninety-four-h of this article;

§ 3. Subdivision 1 and paragraph (a) of subdivision 5 of section 2994-d of the public health law, subdivision 1 as added by chapter 8 of the laws of 2010, paragraph (a) of subdivision 5 as amended by chapter 708 of the laws of 2019, are amended to read as follows:

1. Identifying the surrogate. One person from the following list from the class highest in priority when persons in prior classes are not reasonably available, willing, and competent to act, shall be the surrogate for an adult patient who lacks decision-making capacity. However, such person may designate any other person on the list to be surrogate, provided no one in a class higher in priority than the person designated objects:

(a) A guardian authorized to decide about health care pursuant to article eighty-one of the mental hygiene law or article seventeen-A of the surrogate's court procedure act;

(b) The spouse, if not legally separated from the patient, or the domestic partner;

(c) A ~~[son or daughter]~~ child eighteen years of age or older;

(d) A parent;

(e) A ~~[brother or sister]~~ sibling eighteen years of age or older;

(f) A close friend[-];

(g) the Willowbrook consumer advisory board for members of the Willowbrook class who are fully represented by the consumer advisory board, as provided in section twenty-nine hundred ninety-four-h of this article;

(h) A surrogate decision-making committee under article eighty of the mental hygiene law, for persons eligible for such decision-making, provided that as an alternative such decision may also be made pursuant to subdivision five of section twenty-nine hundred ninety-four-g of this article.

(a)(i) Treatment would be an extraordinary burden to the patient and an attending practitioner determines, with the independent concurrence of another physician, nurse practitioner or physician assistant, that, to a reasonable degree of medical certainty and in accord with accepted medical standards, (A) the patient has an illness or injury which can be expected to cause death within ~~[six months]~~ one year, whether or not treatment is provided; or (B) the patient is permanently unconscious; or

(ii) The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition, other than mental illness or intellectual or developmental disability, as determined by an attending practitioner with the independent concurrence of another physician, nurse practitioner or physician assistant to a reasonable degree of medical certainty and in accord with accepted medical standards.

§ 4. The public health law is amended by adding a new section 2994-h to read as follows:

§ 2994-h. Health care decisions for intellectually or developmentally disabled persons. With respect to an intellectually or developmentally disabled person:

1. Notice of a determination that a surrogate will make health care decisions because the patient has been determined to lack decision-making capacity shall promptly be given:

(a) to the patient unless, due to a medical condition other than an intellectual or developmental disability (such as unconsciousness) it is medically certain that the patient is unable to comprehend the information; and

(b) as otherwise provided by paragraph (a) of subdivision four of section twenty-nine hundred ninety-four-c of this article.

2. No health care decision shall be influenced in any way by a presumption that people with an intellectual or developmental disability are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to people without an intellectual or developmental disability.

3. For an intellectually or developmentally disabled person, 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 practitioner shall notify:

(a) the intellectually or developmentally disabled person unless, due to a medical condition other than intellectual or developmental disability (such as unconsciousness) it is medically certain that the patient is unable to comprehend the information;

(b) 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 services; and

(c) 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 their designee.

4. Agencies or organizations described above and mental hygiene legal service:

(a) must adopt and disclose upon request a practical means to be notified at any time by an attending practitioner;

(b) may waive the right to be notified at any time; and

1 (c) after notice of a proposed withdrawal of life sustaining treat-
2 ment, should respond as soon as reasonably possible. If all notified
3 parties respond that they do not object, the decision may be implemented
4 without regard to the forty-eight hour notification period.

5 5. An inability to notify an agency or organization or the mental
6 hygiene legal service after a good faith attempt to do so, or the
7 absence of a response from any such entity after notification, shall not
8 require a delay in the issuance of an order not to resuscitate.

9 6. (a) If an agency, organization or mental hygiene legal service
10 participates in the treatment meeting at which a decision by a surrogate
11 is made to withdraw or withhold life-sustaining treatment, such partic-
12 ipation shall be considered notice to the participating party for
13 purposes of paragraph (b) of subdivision three of this section and no
14 further notice to such entity shall be necessary, but all rights to
15 object are preserved.

16 (b) For purposes of this paragraph, a "treatment meeting" is a meeting
17 (in person, or by any other means allowing communication by all partic-
18 ipants) to review treatment options with and obtain a decision by the
19 surrogate pursuant to this article, and that includes the attending
20 practitioner, the surrogate, at least one other health or social
21 services practitioner involved in provision of care to the patient, and
22 such other persons as the attending practitioner or surrogate might
23 invite for this purpose. The treatment meeting shall be documented in
24 the medical record.

25 7. (a) A health care decision made pursuant to this article shall be
26 suspended, pending judicial review or withdrawal of the objection,
27 except if the suspension would in reasonable medical judgment be likely
28 to result in the death of the intellectually or developmentally disabled
29 person, in the event of an objection to that decision at any time by
30 persons entitled to notification under subdivision one of this section.

31 (b) Such objection shall occur orally or in writing. Notwithstanding
32 the foregoing, in cases where the attending practitioner has notified
33 the agency or organization and the mental hygiene legal service of the
34 entry of an order not to resuscitate pursuant to subdivision one of this
35 section, and if such notice includes either the practitioner's state-
36 ment of the diagnostic and prognostic basis for the medical determi-
37 nation in support of the order or an excerpt from the patient's medical
38 record that is sufficient to support such determination, (i) an order
39 not to resuscitate shall not be stayed by an objection by such persons
40 unless the objection is accompanied by a written statement by the
41 objecting party setting forth a basis for asserting that a standard in
42 this article for entering such an order has not been met; and (ii) if
43 the basis relates to the failure to meet medical criteria in this arti-
44 cle for the issuance of the order, the written statement must be based
45 on information from or consultation with a physician, physician's
46 assistant or nurse practitioner.

47 8. For purposes of the surrogate priority list under section twenty-
48 nine hundred ninety-four-d of this article, the Willowbrook consumer
49 advisory board shall be the surrogate for any person who was a resident
50 of the former Willowbrook state school on March seventeenth, nineteen
51 hundred seventy-two, and for those individuals who were in community
52 care status on that date and subsequently returned to Willowbrook or a
53 related facility, who are fully represented by the consumer advisory
54 board and who have no guardians appointed, and where persons in classes
55 described in paragraphs (a), (b), (c), (d), (e) and (f) of subdivision
56 one of section twenty-nine hundred ninety-four-d of this article are not

reasonably available, willing, and competent to act. However, with respect to a decision to withdraw or withhold life-sustaining treatment, as an alternative, such decision may also be made pursuant to subdivision five of section twenty-nine hundred ninety-four-g of this article.

§ 5. Section 2994-m of the public health law is amended by adding two new subdivisions 7 and 8 to read as follows:

7. Surrogate decision-making committees. A decision by a surrogate decision-making committee described in article eighty of the mental hygiene law for an intellectually or developmentally disabled person in any setting shall not be subject to review by an ethics review committee or other dispute resolution process described in this section.

8. Special proceeding. Nothing in this section shall preclude a person connected with the case from seeking judicial relief from a court of competent jurisdiction before, during or after an ethics committee review.

§ 6. Subdivision 1 of section 2994-t of the public health law, as added by chapter 8 of the laws of 2010, is amended to read as follows:

1. The commissioner, in collaboration with the commissioner of the office of mental health and the commissioner of the office for people with developmental disabilities, shall establish such regulations as may be necessary to implement this article.

§ 7. Subdivision 26 of section 2994-a of the public health law, as amended by chapter 619 of the laws of 2024, is amended to read as follows:

26. "Person connected with the case" means the patient, any person on the surrogate list, a parent or guardian of a minor patient, the hospital administrator, an attending practitioner, any other health or social services practitioner who is or has been directly involved in the patient's care, and any duly authorized state agency, including the facility director or regional director for a patient transferred from a mental hygiene facility and the facility director for a patient transferred from a correctional facility and any person entitled to notice under section twenty-nine hundred ninety-four-h of this article, relating to decisions to withdraw or withhold life sustaining treatment for intellectually or developmentally disabled persons.

§ 8. Subdivision 6 of section 2994-dd of the public health law, as amended by chapter 29 of the laws of 2025, is amended to read as follows:

6. (a) The commissioner may authorize the use of one or more alternative forms for issuing a nonhospital order not to resuscitate (in place of the standard form prescribed by the commissioner under subdivision two of this section). Such alternative form or forms may also be used to issue a non-hospital do not intubate order.

(b) Any such alternative forms intended for use for persons with developmental disabilities or persons with mental illness who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to article eighty-one of the mental hygiene law or article seventeen-A of the surrogate's court procedure act must also be approved by the commissioner of developmental disabilities or the commissioner of mental health, as appropriate.

(c) An alternative form under this subdivision shall otherwise conform with applicable federal and state law.

(d) A medical order for life-sustaining treatment (MOLST) form in the version previously approved by the commissioner, and the commissioners of mental health and the office for people with developmental disabilities, meets the requirements of this section, provided that the commis-

1 sioner may authorize updated versions of the MOLST form as needed,
2 subject to paragraph (b) of this subdivision. The MOLST form and guid-
3 ance and checklists for using the MOLST form for any patient in any
4 setting shall be posted on the department's website.

5 (e) This subdivision does not limit, restrict or impair the use of an
6 alternative form for issuing an order not to resuscitate in a general
7 hospital or residential health care facility under article twenty-eight
8 of this chapter or a hospital under subdivision ten of section 1.03 of
9 the mental hygiene law [or a facility certified or operated by the
10 office for people with developmental disabilities].

11 § 9. Section 1750-b of the surrogate's court procedure act is REPEALED
12 and a new section 1750-b is added to read as follows:

13 § 1750-b. Life-sustaining treatment decisions for persons with intellec-
14 tual or developmental disabilities

15 1. Decisions to withdraw or withhold life-sustaining treatment for
16 persons who have been found, pursuant to the provisions of this article,
17 to lack capacity to make health care decisions, or for persons for whom
18 no guardian has been appointed pursuant to section seventeen hundred
19 fifty or seventeen hundred fifty-a of this article, but who have an
20 intellectual or developmental disability, as defined in section 1.03 of
21 the mental hygiene law shall be governed by:

22 (a) article twenty-nine-C of the public health law (health care agents
23 and proxies) if applicable; or

24 (b) article twenty-nine-CCC of the public health law with respect to
25 nonhospital orders not to resuscitate if applicable; or

26 (c) article twenty-nine-CC of the public health law, for all other
27 health care decisions, without regard to where the decision is made or
28 where the care is provided.

29 2. With respect to decisions made pursuant to subdivision one of this
30 section, outside of a hospital or hospice as those terms are defined in
31 section twenty-nine hundred ninety-four-a of the public health law:

32 (a) "attending practitioner" shall mean a practitioner who has primary
33 responsibility for the treatment and care of the patient. Where more
34 than one practitioner shares such responsibility, or where a practition-
35 er is acting on the attending practitioner's behalf, any such practi-
36 tioner may act as an attending practitioner pursuant to this article;
37 and

38 (b) the commissioner of the office for people with developmental disa-
39 bilities may promulgate regulations setting forth a process for the
40 resolution of disputes, provided that in a residential facility licensed
41 or operated by the office for people with developmental disabilities
42 such process shall include review by a committee similar to the ethics
43 review committee, but with composition and procedures promulgated by the
44 commissioner of such office.

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