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The Legacy of *Cruzan*: Balancing the Moral Agency of Surrogates and the State

Margie Hodges Shaw
University of Rochester School of Medicine and Dentistry

Timothy E. Quill
University of Rochester School of Medicine and Dentistry, Rochester

Bernard L. Sussman
University of Rochester School of Medicine and Dentistry, Rochester

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THE LEGACY OF *CRUZAN*: BALANCING THE MORAL AGENCY OF SURROGATES AND THE STATE

Margie Hodges Shaw, Timothy E. Quill & Bernard L. Sussman*

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I. INTRODUCTION

BIOETHICS scholars applauded the *Cruzan v. Director, Missouri Department of Health*¹ decision for encouraging the creation of “mechanisms to safeguard the interests of people who become incapacitated at the end of life.”² The legacy of the *Cruzan* decision is wider reaching than early literature suggests. At its core, *Cruzan* is about an incapacitated person’s fundamental liberty interest to be free of unwanted medical treatment and the role of the government in defining a process to protect that right.³ The reasoning in *Cruzan* impacts a patient population that includes both those who were previously capacitated and others who were never capacitated. It affects an incapacitated individual’s liberty interest to receive the kinds of medical treatment they could choose if capacitated. In this article, the authors review the case of a never capacitated patient in light of the *Cruzan* decision to consider the intended and unintended consequences of legal requirements created by New York State (NYS) to safeguard the interests of patients with intellectual and developmental disabilities (IDD). Inconsistent with the funda-

* The authors are from the Schyve Center for Biomedical Ethics, Division of Medical Humanities and Bioethics, University of Rochester School of Medicine and Dentistry, Rochester, New York.

1. 497 U.S. 261 (1980).

2. Sara Taub, *Departed, Jan 11, 1983; At Peace, Dec 26, 1990*, AMA J. ETHICS (Nov. 2001), <https://journalofethics.ama-assn.org/article/commemorative-issue-departed-jan-11-1983-peace-dec-26-1990/2001-11> [<https://perma.cc/42XN-L6HG>].

3. *Cruzan*, 497 U.S. at 277–79; see also *Washington v. Harper*, 494 U.S. 210, 221–22 (1990); *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

mental principles in *Cruzan*, current procedures set forth by NYS favor ensuring access to aggressive disease-directed therapies and can thereby impede the fundamental liberty interest of a patient with IDD to be free of intrusive medical treatment at the end of life. While the authors focus on one patient in one state, this case illuminates issues and concerns involving all incapacitated patients, which the authors hope will inform discussions across jurisdictions.

II. CASE

Stephen D.,⁴ a thirty-year-old man, had been in declining health with mounting medical problems for one year. At the age of four, he was struck by a car resulting in traumatic brain injury and quadriplegia. Intellectually disabled and nonverbal, he remained dependent on his parents for all daily activities. For twenty-six years, Stephen D. had been lovingly cared for at home by his parents. Multiple medical problems developed over his lifetime, including a seizure disorder, spastic tetraplegia that required treatment with a Baclofen intrathecal pump, osteoporosis, scoliosis with resulting restrictive lung disease, ulcerative colitis, and the need for nutritional supplementation through a gastric feeding tube.

New and worsening medical problems included progressive difficulty swallowing with aspiration, weight loss, severe and recurring *Clostridium difficile* colitis, disordered breathing, and periods of apnea. Stephen D.'s parents recognized his declining well-being in his loss of appetite, chronic pain from skeletal deformities and muscle spasms, withdrawal from activities at group programs, disengagement from family life, and indifference to previous sources of enjoyment such as television.

A sleep medicine evaluation established a diagnosis of advanced central and obstructive sleep apnea. Tracheotomy and mechanical ventilation at night were recommended. The parents recoiled from this recommendation. They questioned the treatment's ability to reverse the burdens of their son's many medical problems or to improve the declining quality of his life. Based on his prolonged recovery from previous medical procedures and the agitation caused by only supplemental nasal oxygen, the parents thought their son would be terrified by tracheotomy, mechanical ventilation, and prolonged hospitalization.

Primary care and consulting physicians supported the parents' wish to reject surgery and mechanical ventilation for their son. An order to forego intubation and cardiopulmonary resuscitation (CPR) was unanimously viewed by the treatment teams as consistent with the parents' judgment about their son's best interest. To implement such a medical order in NYS, a concurrence of the Office for Persons with Developmental Disabilities (OPWDD) was required. Before this process could be completed, Stephen D. developed pneumonia and sepsis. His parents

4. The authors acknowledge and thank the mother of Stephen D. for permission to share her son's story. Note, Stephen D. is a pseudonym.

were determined to avoid hospitalization because of their son's previous severe distress in hospitals and their belief that CPR and its consequences would be excessively burdensome.

Antibiotics and morphine were provided at home, where managing their son's condition soon became overwhelming. Upon medical advice, the parents brought their son to a hospital emergency department where pneumonia and sepsis were confirmed. The parents were given the option to admit their son to the intensive care unit for intubation and mechanical ventilation or to take their son home against medical advice. No alternative options between these two extremes were available because it was not possible to obtain OPWDD concurrence over the weekend. Wishing to emphasize their son's comfort, the parents chose to return home despite having limited medical and nursing support. Hospice services were unavailable in the absence of a concurring OPWDD decision about goals of care. The emergency department notified Adult Protective Services (APS) of the parents' decision to take their son home against medical advice. As a result, police were contacted by APS and visited the family home to attempt to persuade the parents to bring their son back to the hospital. Stephen D. died at home about fifteen hours later. The family called 911, and the police returned to investigate, treating Stephen D.'s deathbed as a potential crime scene. The parents contended with the threat of criminal charges until the county medical examiner determined that the cause of death was pneumonia.

III. DISCUSSION

It is well recognized that patients with capacity have the legal right to consent to or to refuse to consent to any and all treatment options, including life-sustaining treatment (LST).⁵ This guarantee is founded on respect for the patient's right of self-determination, often identified as respect for autonomy.⁶ Self-determination and the authority to consent to or refuse treatment requires capacity to understand and evaluate.⁷ The right of patients to refuse LST, however, is not absolute. States have interests that sometimes allow the infringement of individual rights.⁸ The state's interest in preserving life is particularly strong, encompassing two

5. See *Harper*, 494 U.S. at 221; *Breithaupt v. Abram*, 352 U.S. 432, 439 (1957); *Salgo v. Leland Stanford Jr. Univ. Bd. Trs.*, 317 P.2d 170, 181 (Cal. Ct. App. 1957); *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972); *Natanson v. Kline*, 350 P.2d 1093, 1101-02 (Kan. 1960); *In re Quinlan*, 355 A.2d 647, 663-64 (N.J. 1976).

6. See *Canterbury*, 464 F.2d at 780.

7. See *id.* ("True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each.")

8. See *Satz v. Perlmutter*, 362 So. 2d 160, 162 (Fla. Dist. Ct. App. 1978); *In re Spring*, 405 N.E.2d 115, 123 (Mass. 1980); *Comm'r of Corr. v. Myers*, 399 N.E.2d 452, 456 (Mass. 1979); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977); *In re Torres*, 357 N.W.2d 332, 339 (Minn. 1984); *In re Colyer*, 660 P.2d 738, 743 (Wash. 1983); Carol Ann Calabrese, Comment, *In re Storar: The Right to Die and Incompetent Patients*, 43 U. PITT. L. REV. 1087, 1092 (1982).

concerns: interest in protecting the individual life in question and interest in promoting the value of human life in general.⁹ In *Cruzan*, the Supreme Court reconfirmed a capacitated patient's authority to forgo LST even when the state asserts an interest in protecting that patient's life.¹⁰

When patients lack the capacity for self-determination, particular states disagree on the best process to both safeguard the interests of the individual patient and promote other state interests. NYS distinguishes the decision-making processes for the previously capacitated and the never capacitated.¹¹ This distinction reveals discriminatory beliefs about the never capacitated patient and results in disparate treatment, disrespect for the moral authority of the family, and misdirected state involvement.

A. INCAPACITATED PATIENTS

How a patient who lacks the capacity to make medical decisions can be autonomous and self-determining is a complex consideration. Scholars have argued that patients who lack capacity are not autonomous; therefore, respecting the autonomy of an incapacitated patient is impossible.¹² Courts often strain logic discussing autonomy and self-determination. For example, a New Jersey court reasoned "that the right of self-determination should not be lost merely because an individual is unable to sense a violation of it."¹³ In *Cruzan*, the United States Supreme Court did not recognize the patient's autonomy, but rather considered the constitutionality of a state regulation to verify the patient's previously expressed wishes.¹⁴ In the absence of a specific and relevant advance directive, consistent with *Cruzan*, the role of the surrogate is not to promote the patient's autonomy but rather to demonstrate respect for the patient's previously expressed values and preferences by making decisions in accord with those values and preferences.¹⁵ *Cruzan* explicitly did not create

9. See, e.g., MO. ANN. STAT. § 459.055 (West 2018).

10. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286–87 (1980). In matters of public health or security, courts may preference the interest of the state over the interest of the individual. *Jacobson v. Massachusetts*, 197 U.S. 11, 25 (1905); *Myers*, 399 N.E.2d at 455–56.

11. For a detailed analysis of, and argument to consolidate, existing NYS surrogacy laws, see N.Y. TASK FORCE ON LIFE & THE LAW, RECOMMENDATIONS FOR AMENDING THE FAMILY HEALTH CARE DECISIONS ACT TO INCLUDE HEALTH CARE DECISIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES AND PATIENTS IN OR TRANSFERRED FROM MENTAL HEALTH FACILITIES 4–5 (2016), https://www.health.ny.gov/regulations/task_force/reports_publications/docs/2016-06_recommendations_for_amending_fhda.pdf [https://perma.cc/M7SL-JKQY].

12. Daniel Brudney, *Choosing for Another: Beyond Autonomy and Best Interests*, 39 HASTINGS CTR. REP. 31, 34 (2009).

13. *Cruzan*, 497 U.S. at 273 (citing *In re Conroy*, 486 A.2d 1209, 1229–33 (N.J. 1985)); see also Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 50–51 (1990) (substituted judgment, even when supported by evidence of the patient's wishes, purports to promote the patient's right of self-determination precisely when the patient lacks the capacity for self-determination around medical decisions).

14. *Cruzan*, 497 U.S. at 280.

15. Brudney, *supra* note 12, at 36. Surrogate decision makers can have significantly different evidence about the previous expressions of choice and wishes. The goal is to

a constitutional requirement that the state recognize the authority of a family decision maker.¹⁶ Nonetheless, the authors suggest the state's interest in safeguarding the welfare of the incapacitated is best achieved, whenever possible, by giving primacy to family members' understanding of the patient's lived experience.¹⁷

B. THE MORAL AUTHORITY OF THE FAMILY

In *In re Quinlan*, the Supreme Court of New Jersey granted a father the right to discontinue life-sustaining respirator support on behalf of his daughter, a previously capacitated adult patient.¹⁸ In that case, foundational to the development of the rights of surrogates under the Constitution, both the lower court and the Supreme Court of New Jersey concluded that the evidence of the patient's wishes "lacked significant probative weight" and was insufficient to determine "what she would want done in such a contingency as now exists."¹⁹ Unable to rely on the doctrines of informed consent and substituted judgment as they existed, the court nonetheless recognized the moral authority of the family over the objections of the doctors and the State.²⁰ Without evidence of the patient's moral views, the New Jersey court determined the father to be the appropriate surrogate to express the moral views of the patient regarding respirator support.²¹ The language of the decision indicates the court agreed with the remedy sought by the father.²²

Not all state courts have been inclined to recognize the moral authority of family to make medical decisions for incapacitated patients. For example, in *In re Storar*, the New York Court of Appeals denied a devoted mother the authority to refuse LST on behalf of her son.²³ Because the patient never had capacity to make medical decisions, the court asserted that "it is unrealistic to attempt to determine whether he would want to continue potentially life prolonging treatment if he were competent."²⁴

make the decision the patient *would* make under the circumstances. Daniel Brudney argues for the need to respect both self-determination and authenticity of the patient. *Id.* Authenticity sometimes "involve false beliefs, poor reasoning, and so forth." *Id.*

16. *Cruzan*, 497 U.S. at 286.

17. *Id.* (citing *Michael H. v. Gerald D.*, 491 U.S. 110, 131–32 (1989); *Parham v. J.R.*, 442 U.S. 584, 620 (1979)).

18. 355 A.2d 647, 671 (N.J. 1976).

19. *Id.* at 653.

20. *Id.* at 671. The court also put limitations on this authority, requiring the physicians and, oddly, a hospital ethics committee to conclude that there was no reasonable possibility Quinlan would emerge "from her present comatose condition to a cognitive, sapient state" *Id.*

21. *Id.* at 664.

22. *Id.* at 662. The language of the decision indicates the court was deeply troubled by the condition of the patient. *Id.* at 657–58 (complimentary of the moral decision-making process by the father); *id.* at 664 (observing, without citing supportive evidence, the "overwhelming majority" of members of society would make the same decision under similar circumstances).

23. *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981). For another example, see *In re Joseph P.*, 966 N.Y.S.2d 622, 624 (N.Y. App. Div. 2013).

24. *Storar*, 420 N.E.2d at 72.

One can differentiate *Quinlan* and *Storar* by the characterization of the status of the patients—one patient was previously capacitated and the other was never capacitated. However, this characterization would fail to acknowledge that the *Quinlan* court found the evidence of previously expressed wishes to be insufficient.²⁵ The differences in these cases include what the respective courts deemed to be an undesirable outcome: in *Quinlan*, the court decided that life was undesirable,²⁶ and in *Storar*, the court concluded that death was undesirable.²⁷ Both of these determinations are value-based. When there is disagreement on the rightness of outcomes based upon values, how decisions are made becomes especially important.

When unable to rely upon the doctrines of informed consent and substituted judgment, the surrogate is to make the decision that is in the patient's "best interest." The best interest standard was historically intended to be objective and represent what *the* reasonable person would decide. Influences on these decisions, however, are intensely personal and are often grounded in values and beliefs rather than logic alone. The circumstances and time in which one lives inform these values and beliefs. Early decisions relying on the best interest standard authorized medical interventions, since the alternative of death was not considered preferable.²⁸ Advances in medical technologies, such as the respirator support used in the care of the patient in *Quinlan*, caused some to consider limitations on use of LSTs.²⁹

Today, it is understood that reasonable people may disagree about what is in their best interest in identical clinical situations. Therefore, there is no single response to the question of what is in a patient's best interest. In *Cruzan*, the Supreme Court recognized the authority of the State to create procedural rules for adjudication of questions about the scope of surrogate decision-making while citing previous decisions that upheld the constitutionality of the State's "favored treatment of traditional family relationships."³⁰ The State of Missouri required the family to present "clear and convincing" evidence of the patient's previous wishes when making decisions about forgoing any LST.³¹ In requiring the surrogate to find and rely upon evidence of the patient's previously known values, perspectives, and wishes, the Court attempted to demonstrate respect for the individual. Daniel Brudney, citing Ronald Dworkin, argues that demonstrating respect for the "integrity" and "authenticity" of each person is the central moral obligation in surrogate decision-mak-

25. *Quinlan*, 355 A.2d at 653.

26. *Id.* at 663.

27. *Storar*, 420 N.E.2d at 73.

28. *See, e.g., id.*

29. *See, e.g., Quinlan*, 355 A.2d at 671–72.

30. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286 (1980) (citing *Michael H. v. Gerald D.*, 491 U.S. 110 (1989); *Parham v. J.R.*, 442 U.S. 584 (1979)).

31. *Id.* at 280.

ing.³² The question the authors address is how to best meet this obligation.

C. STATE INVOLVEMENT

Following *Cruzan*, NYS created multiple laws and regulations governing medical decision-making for adult patients who lack capacity.³³ The laws regulating medical decisions for individuals with IDD establish substantive and procedural limitations on the decision-making role of family surrogates. The existence of these legal safeguards arises from historical evidence of abuse and neglect of people with disabilities.³⁴ Under NYS common law, persons with mental retardation could not refuse LST, nor could a surrogate decision maker refuse LST on their behalf.³⁵ This led some family members of persons with IDD to seek legislative relief for painful and intrusive LSTs that a person with capacity might reasonably decide to forgo.³⁶ In response, NYS passed the Health Care Decisions Act for Persons with Mental Retardation (HCDA) in 2003, expanding the rights of guardians to make health care decisions on behalf of intellectually incapacitated patients.³⁷

32. Brudney, *supra* note 12, at 35 (citing RONALD DWORKIN, *LIFE'S DOMINION* (First Vintage Book ed., 1994)).

33. See N.Y. PUB. HEALTH LAW §§ 2960–2994, 2994-aa–2994-gg (McKinney 2019); N.Y. MENTAL HYG. LAW §§ 80.01–13 (McKinney 2019); N.Y. SURR. CT. PROC. ACT §1750-b (McKinney 2019); N.Y. COMP. CODES R. & REGS. tit. 14, §§ 27.9, 527. 8, 633.11 (2019); N.Y. TASK FORCE ON LIFE & THE LAW, *supra* note 11, at 4–7.

34. See David J. Rothman & Sheila M. Rothman, *The Litigator as Reformer*, in *MENTAL RETARDATION IN AMERICA: A HISTORICAL READER* 445, 445–46 (Steven Noll & James W. Trent Jr. eds., 2004). The Willowbrook State School in NYS is often cited as a particularly egregious example of mistreatment of institutional residents. See Walter M. Robinson & Brandon T. Unruh, *The Hepatitis Experiments at the Willowbrook State School*, in *THE OXFORD TEXTBOOK OF CLINICAL RESEARCH ETHICS* 80, 80 (Ezekiel J. Emanuel et al. eds., 2008). Public outrage at the revelations of abhorrent treatment of residents at Willowbrook led to legislation specifically designed to protect individuals with disabilities from similar mistreatment in the future. See DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS: BRINGING THE MENTALLY DISABLED INTO THE COMMUNITY* 45 (2005). Safeguards against the possibility of family and/or medical misconduct were seen as necessary to prevent abuses of the past. *Id.* at 151.

35. See *In re Storar*, 420 N.E.2d 64, 72 (N.Y. 1981) (noting that the common law requires “clear and convincing” evidence of the patient’s intentions to refuse or withdraw LSTs); *People v. Eulo*, 472 N.E.2d 286, 296 (N.Y. 1984) (holding that, absent legislation, a surrogate does not have the authority to determine a patient’s quality of life is such that treatment should be withdrawn or withheld); *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 191 (N.D.N.Y. 2002) (citing *In re O’Connor*, 531 N.E.2d 607, 612 (N.Y. 1988) (stating that the doctrine of informed consent is “personal and, under existing law in this State, [can] not be exercised by a third party when the patient is unable to do so”)).

36. See *In re M.B.*, 846 N.E.2d 794, 796 (N.Y. 2006).

37. Health Care Decisions Act for Persons with Mental Retardation, ch. 500, § 3, 2002 N.Y. Laws (codified at N.Y. SURR. CT. PROC. ACT § 1750-b (McKinney 2019)). Guardianship begins with a diagnosis: two health care providers must determine the individual is “incapable to manage him or herself and/or his or her affairs by reason of mental retardation and that such condition is permanent in nature or likely to continue indefinitely.” *Id.* Subsequent amendments broadened the scope to encompass people with developmental disabilities. See, e.g., Act of July 3, 2007, ch. 105, § 1, 2007 N.Y. Laws (codified at N.Y. SURR. CT. PROC. ACT § 1750-b). The HCDA recognizes that persons who satisfy the conditions for guardianship may have the ability to make health care decisions. N.Y. SURR. CT.

Although the HCDA codifies beliefs about the role of family that are “deeply rooted in this Nation’s history and tradition,”³⁸ recognizing family members as natural advocates for adults with IDD, it does so ambivalently. Historical abuses revealed both family members and medical professionals to be complicit in biases rooted in the devaluation of the lives of persons with disabilities.³⁹ The HCDA consequently incorporates limits on the authority of family surrogates.⁴⁰ Summaries of the law describe a process that allows the guardian of a person with IDD to make all health care decisions that the patient could make if they had capacity, including LST.⁴¹ This description is misleading. Patients with capacity can make decisions about LST in all medical circumstances. The HCDA, in contrast, regulates a guardian or qualified family member’s ability to make the same decisions on behalf of a patient with IDD by a burdensome and discriminatory process. It allows the refusal or withdrawal of LST only under limited medical conditions.⁴² The law places an affirmative obligation on the surrogate “to advocate for the full and efficacious provision of health care, including life-sustaining treatment.”⁴³ While the HCDA attempted to balance the competing interests of respecting the dignity of the individual and protecting the individual from discriminatory decisions, the law strongly favors the prolongation of life over decisions to withhold LST.

*In re Joseph P.*⁴⁴ illustrates the application of the NYS laws. Joseph P. was a fifty-five-year-old man with profound IDD who lived in a group home.⁴⁵ Other medical problems included cerebral palsy, spinal curvature, and spastic quadriplegia.⁴⁶ When hospitalized for aspiration pneumonia caused by dysphagia, his parents—who were his legal guardians— withheld consent for placement of a feeding tube.⁴⁷ The attending physician and chief medical officer of the hospital where Joseph P. was being treated supported the parents’ decision.⁴⁸ In compliance with NYS law, the hospital notified the OPWDD of the decision to withhold LST.⁴⁹ Concurring physicians stated that the proposed feeding tube would constitute an “extraordinary burden” on the patient because he would have difficulty with the necessary reassignment from his group home where he

PROC. ACT § 1750-b(2). Under these circumstances, the guardian is appointed for the purpose of making other kinds of decisions, such as financial, educational, or housing decisions. *Id.* § 1750.

38. *Moore v. City of E. Cleveland*, 431 U.S. 494, 503 (1977) (plurality opinion).

39. *See infra* note 34.

40. *See* § 1750-b(1).

41. NYS OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, HEALTH CARE CHOICES: WHO CAN DECIDE? 13–16 (2012), https://opwdd.ny.gov/sites/default/files/documents/Health_Care_Choices_2_14_Layout_5.pdf [<https://perma.cc/Y7L8-RA7N>].

42. *See supra* Table 1.

43. § 1750-b.

44. 966 N.Y.S.2d 622 (N.Y. App. Div. 2013).

45. *Id.* at 623.

46. *Id.*

47. *Id.*

48. *Id.* at 623–24.

49. *See id.* at 624.

had been a resident for twenty-seven years.⁵⁰ He also would likely need to be restrained to prevent his removal of the feeding tube, and he would regularly need deep suctioning which is very uncomfortable.⁵¹ Finally, the feeding tube would not address the underlying “medical condition that . . . is irreversible and . . . will continue indefinitely.”⁵² OPWDD objected to the decision and filed a lawsuit to compel insertion of the feeding tube. The New York trial court held the parents met the statutory criteria (extraordinary burden) for refusal of LST and denied the state agency’s petition to authorize surgical insertion of a feeding tube.⁵³ The only question before the court of appeals was whether or not the “burden” of the treatment on the patient was “extraordinary.”⁵⁴

NYS requires the same “clear and convincing” standard as Missouri that was upheld in *Cruzan*.⁵⁵ The New York Supreme Court, Appellate Division, held the parents failed to establish by clear and convincing evidence that the treatment would impose an extraordinary burden on their son.⁵⁶ The court based the decision on the testimony of a physician and nurse at the OPWDD group home who reported that Joseph P. had been alert and seemingly pain free in his life before hospitalization and thought the future burdens of life with a feeding tube did not “outweigh any pleasure, emotional enjoyment or other satisfaction that he may yet be able to derive from life.”⁵⁷

The case of Stephen D., presented above, again demonstrates how safeguards in NYS laws governing refusal of LST for persons with IDD may override the judgment of family and court-appointed guardians regarding best interests. In Stephen D.’s case, OPWDD did not review the parental decision to withhold intubation and CPR because the medical problem arose acutely and OPWDD review could not be initiated rapidly enough on a weekend. Hospital physicians were aware of legal requirements to obtain OPWDD assent to a plan to forgo LST for individuals with IDD, and the physicians informed Stephen D.’s parents that, if hospitalized, Stephen D. would need intubation and full critical care measures. Even if timely OPWDD review had been available, the possibility existed that OPWDD would reject the parents’ decision and a legal process, as in the case of Joseph P., would ensue. This outcome was unacceptable to Stephen D.’s parents who felt their first responsibility was to protect their son from unwarranted suffering and excessively burdensome medical care.

50. *See id.* at 624–25.

51. *Id.*

52. *Id.* at 624.

53. *Id.*

54. *Id.*

55. *See Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 265 (1990).

56. *Joseph P.*, 466 N.Y.S.2d at 625.

57. *Id.*

IV. CONCLUSION

The historical motivation to protect persons with IDD is understandable. The NYS laws reflect legislative caution born of that history. Regrettably, an unintended consequence of a focus on historical abuses and the need of the state to protect vulnerable populations can harm persons with IDD when considering medically appropriate care at the end of life. The safeguards and limitations of these NYS laws constitute a legal state of mistrust that clouds the moral agency of family surrogates. The case of Stephen D. demonstrates the hazards of these restrictions on the execution of his parental guardians' obligations and desires to care for their son. His parents were compelled to make a choice that may have denied their son optimal end-of-life care in his final hours and that subjected them to investigation for criminal activity. No previously capacitated NYS resident or their family would have been subject to this scrutiny, suspicion, or denial of access to medically necessary care.

Different well-intentioned, caring surrogates may reach different conclusions about their incapacitated family member's best interest. Joseph P.'s parental guardians thought that placement of a gastric feeding tube would prove excessively burdensome.⁵⁸ Physicians at the hospital treating him for aspiration pneumonia agreed, as did the trial court.⁵⁹ The appellate court, however, overruled the decision on the strength of conflicting testimony from a nurse and a physician at the patient's OPWDD group home.⁶⁰ Both opinions might well be "reasonable" under such complex circumstances. Conscientious efforts at assessing an incapacitated person's best interest may result in different conclusions. However, there is no good reason to favor the state's authority in these decisions over committed and responsible family. Rather, family may be in the best position to apply available knowledge of an incapacitated individual's experience and preferences that may have bearing on medical decisions. It is discriminatory to recognize the natural role of family as surrogate decision makers for incapacitated individuals but then create distinctive obstacles to their informed judgments on behalf of people with IDD.

Decisions about medical care for the terminally and critically ill can be extremely challenging. Physicians will often disagree about their patient's prognosis and best interest. The complex clinical and moral decisions for patients who lack capacity to be fully self-determining can be addressed through recognition of the natural justification for family to act as surrogates. This is true of parental authority in making end-of-life decisions for children in medically fraught circumstances, as well as for adults who have lost capacity. The same should be true for the family and guardians who act as surrogates for the never capacitated community of persons with IDD.

58. See Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 395-96 (1986).

59. *Joseph P.*, 466 N.Y.S.2d at 264.

60. *Id.* at 265.

In cases where the patient lacks capacity, it is necessary to determine both *who* is the appropriate surrogate decision maker and *what* kinds of medical decisions the surrogate has the authority to make. It also is important to consider *how* surrogates are to make the decisions. Historically, courts failed to consider that individuals with IDD were capable of making decisions or having values, beliefs, or preferences worthy of consideration. Although in some instances this is true, this categorical determination is prejudicial. Individuals with IDD perform a wide range of daily activities requiring decisions which reflect how they want to live.⁶¹

The *Cruzan* Court concluded the State could defer to the patient's wishes and set standards to govern determination of her wishes.⁶² The Court also cited previous decisions that upheld the constitutionality of the State's "favored treatment of traditional family relationships."⁶³ To fully respect incapacitated individuals and realize the claims in the HCDA, NYS would need to promote self-determination in patients with IDD where possible and allow the intentions and preferences of such individuals to inform medical decision-making on their behalf. Prioritizing "empirical evidence about what individuals value and how they make decisions," rather than asking what is in another's "best interest," demonstrates respect for the individual.⁶⁴

OPWDD or other agencies in NYS and elsewhere, charged with the welfare of the community of persons with IDD, should have recourse to legal remedies if there is strong evidence of surrogate decisions that justify suspicion of surrogate maleficence or misconduct. There should not, however, be a process that defaults to aggressive interventions at the end of life even when legally recognized family surrogates provide evidence of patient values and preferences to the contrary.

61. See, e.g., Brief of Amici Curiae, The American Association on Intellectual and Developmental Disabilities (AAIDD), and the ARC of the United States, in Support of Petitioner at 13, *Moore v. Texas*, 137 S. Ct. 1039 (2017); see also *The Right to Sexuality*, ATLANTIC (June 14, 2019), <https://www.theatlantic.com/video/index/591280/disability-consent/> [<https://perma.cc/37KW-QASM>].

62. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 284 (1980).

63. *Id.* at 286 (citing *Michael H. v. Gerald D.*, 491 U.S. 110, 131–32 (1989); *Parham v. J.R.*, 442 U.S. 584, 620 (1979)).

64. Daniel P. Sulmasy & Lois Snyder, *Substituted Interest and Best Judgments: An Integrated Model of Surrogate Decision Making*, 304 JAMA 1946, 1946–47 (2010).

TABLE 1
 A Summary of Health Care Decisions for Persons Who Are
 Intellectually Disabled, N.Y. SURR. CT. PROC. ACT
 § 750-b (McKinney 2019).

<p>When a surrogate for a patient with an IDD expresses a decision to withdraw or withhold LST, the attending physician, after confirming the patient lacks capacity to make medical decisions, must consult with a second physician or licensed psychologist to confirm the patient's lack of capacity. Either the attending physician or the consultant must possess specialized training or have experience in providing services to the intellectually disabled. In addition, the attending physician and the consultant must determine that both of the following conditions exist:</p>
<p>(1) the person with disabilities has a medical condition as follows:</p>
<p>(a) a terminal condition, which means “an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year,” N.Y. PUB. HEALTH LAW § 2961 (McKinney 2018); or</p> <p>(b) permanent unconsciousness; or</p> <p>(c) a medical condition other than such person's disabilities which requires LST, is irreversible and which will continue indefinitely; and</p>
<p>(2) the LST would impose an extraordinary burden on the person, in light of:</p>
<p>(a) the person's medical condition, other than the person's disabilities; and</p> <p>(b) the expected outcome of the LST, notwithstanding the person's disabilities.</p>

In the case of a decision to withdraw or withhold artificially provided nutrition or hydration, one of the following additional factors must also be met:

- (1) there is no reasonable hope of maintaining life; or
- (2) the artificially provided nutrition or hydration poses an extraordinary burden.

The law requires notification, at least forty-eight hours before implementation or at the earliest possible time, to (1) the patient (unless such notification would cause injury); (2) the executive director of the agency operating the facility, if the patient lived in an OPWDD operated or certified residential facility and the Mental Hygiene Legal Services (MHLS); or (3) the Commissioner of OPWDD, if the patient did not reside in such a facility.

The law also established seven categories of people who can object to a guardian or qualified family member's decision regarding the withholding or withdrawal of LST. These include (1) the patient; (2) a parent or adult sibling who either resides with the patient or "has maintained substantial and continuous contact" with the patient; (3) the attending physician; (4) any other member of the health care team; (5) the executive director of the agency operating the patient's residential facility; (6) the MHLS; or (7) the Commissioner of OPWDD. The surrogate's decision is suspended if any of the notified parties object and the case proceeds to either a nonbinding dispute mediation process or court review.

