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Note

The Ashley Treatment: The Current Legal Framework Protects the Wrong Rights

*Jillian Kornblatt**

In 2006 two Seattle doctors performed several procedures to attenuate the growth of a profoundly neurologically and cognitively disabled six-year-old girl. When the doctors described the treatment in a medical journal, the story gained worldwide publicity and quickly became the subject of a highly contentious and emotionally charged controversy. As a result, a federally-sanctioned disability rights protection organization conducted an investigation and concluded that the treatment should not have been performed without a court order and that doing so violated the girl's constitutional rights.

Part I of this Note considers the legal framework applied to the treatment decision and how the framework would apply to other children whose parents requested the treatment. Part II then analyzes whether this framework adequately protects the best interests and constitutional rights of potential candidates for this treatment and their parents. The Note concludes that due to its inappropriate focus on the rights to choose to procreate and to be free from bodily invasion, the current framework does not adequately protect the patient's more relevant rights to dignity, freedom from pain, and life or parents' right to make decisions regarding their children. The Note suggests that states should enact statutes narrowly tailored to these cases in order to address and protect the multiple rights and interests involved in these situations. These statutes—which should include procedural safeguards—should allow the treatment when parents and doctors agree that it is in the child's best interest.

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I. BACKGROUND

A. THE TREATMENT.

In October 2006, two endocrinologists described a series of procedures that they combined in a novel way to treat one of their patients, as a “therapeutic option for . . . nonambulatory children with severe, combined neurologic and cognitive impairment[s]. . . .”¹ After discussing the ethical issues involved in the treatments, the doctors concluded that these procedures provided a new option for “nonambulatory, profoundly impaired” children, which—after adequate screening and fully informed consent—parents should be able to elect for their children.²

The endocrinologists’ patient, Ashley, had been diagnosed with static encephalopathy,³ of unknown origin.⁴ Ashley is profoundly “neurologically and cognitively impaired,” with an IQ too low to be tested.⁵ At age six years and seven months, her mental development was at the level of an infant, and she was unable to move, speak, or eat without a feeding tube.⁶ The neurologists, medical geneticists, and developmental pediatricians who examined her concurred that no further development was expected.⁷ Between one and two percent of

1. Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRIC ADOLESCENT MED. 1013, 1013 (2006).

2. *Id.*

3. MedHelp, <http://www.medhelp.org/forums/neuro/archive/4948.html> (last visited Apr. 9, 2009) (“Static encephalopathy is a general term used to describe a general dysfunction in the brain that is not getting worse over time.”).

4. Gunther & Diekema, *supra* note 1, at 1014.

5. *Id.*; DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROT. & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE “ASHLEY TREATMENT,” EXHIBIT O LETTER FROM LARRY JONES, PH.D., J.D., TO ASHLEY’S DAD (June 10, 2004) 2 (2007), available at http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment_Exhibits%20K%20-%20T.pdf [hereinafter LETTER]. Individuals who are too impaired to have their IQs tested are classified as having Mental Retardation, Severity Unspecified, while those with IQs below twenty to twenty-five are classified as having Profound Mental Retardation. AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 42, 44 (4th ed., text rev. 2000).

6. Gunther & Diekema, *supra* note 1, at 1014.

7. *Id.*

children with mental retardation are classified as having Profound Mental Retardation.⁸ These children require life-long care, which is typically done in specialized facilities.⁹

Ashley lived with her siblings and parents, who were her primary caretakers.¹⁰ Ashley's care included "body movement/placement, feeding, cleansing of respiratory tract secretions, facilitation of bowel movements, total body hygiene, etc."¹¹ Using Ashley's vocalizations as cues, Ashley's family developed a variety of routines they believed gave Ashley pleasure. These include frequent moves from room to room of their home, rotating décor in her bedroom, taking her on outings, and sending her to a special school by bus.¹²

When Ashley displayed signs of early puberty and accelerated growth, her parents approached Ashley's doctors with their concerns.¹³ Their primary worry was that despite their intention to care for Ashley at home indefinitely, they would be forced to institutionalize her when she became too large to move without a lift.¹⁴ Additionally, they were concerned about limited mobility, menstrual pain, and discomfort from large breasts, which were common in Ashley's

8. AM. PSYCHIATRIC ASS'N, *supra* note 5, at 44; *see also* Offord Centre for Child Studies, Centre of Knowledge on Healthy Child Development, http://www.knowledge.offordcentre.com/dev_learn/devdis/dev_dd_about.html#dd_03 (last visited Feb. 12, 2009) (on file with journal). "The prevalence rate of Mental Retardation has been estimated at approximately 1%." AM. PSYCHIATRIC ASS'N, *supra* note 5, at 46.

9. Offord Centre for Child Studies, *supra* note 8; *see* AM. PSYCHIATRIC ASS'N, *supra* note 5, at 44.

10. Ashley's Mom & Dad, The "Ashley Treatment," (Jan. 2, 2007, last updated Mar. 25, 2007), <http://ashleytreatment.spaces.live.com/default.aspx> [hereinafter Ashley's Blog]. Ashley's mother and father created a website to provide information about Ashley and her medical treatment amid the growing speculation following the Gunther and Diekema article. Ashley's parents did not reveal their daughter's full name and wrote the blog under the names "Ashley's Mom & Dad" to preserve the family's anonymity. *Id.*

11. DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROT. & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT," EXHIBIT L SPECIAL CHRMC ETHICS COMM. MEETING/ CONSULTATION (MAY, 2004) 2 (2007), *available at* http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment_Exhibits%20K%20-%20T.pdf [hereinafter ETHICS COMMITTEE MEETING].

12. *Id.*

13. Gunther & Diekema, *supra* note 1, at 1014.

14. *Id.*; Ashley's Blog, *supra* note 10.

family.¹⁵

The doctors explained that through growth attenuation treatment, accompanied by a hysterectomy and breast bud removal, many of these potential problems could be limited or avoided.¹⁶ The growth attenuation therapy, performed with high doses of estrogen, was anticipated to achieve a forty percent reduction in expected weight and a twenty percent reduction in expected height.¹⁷ In addition to decreasing the likelihood of needing a lift or being institutionalized, this would allow the family to continue to do the activities Ashley appeared to enjoy and by moving her, increase her circulation and reduce the likelihood of bedsores and scoliosis from immobility.¹⁸

The primary reason for the hysterectomy was to avoid menstrual pain.¹⁹ Additional benefits included eliminating the possibilities of pregnancy through sexual assault or uterine cancer.²⁰ Removal of the breast buds, small mammary glands, was to prevent discomfort from a wheelchair strap across her chest or the chafing straps of a brazier.²¹ Additional benefits were preventing the possibility that fully-developed breasts could sexualize her toward possible care-takers and avoiding possible breast cancer.²²

Before the procedures were performed, Ashley's parents and doctors met with the Children's Hospital Ethics Committee.²³ The committee noted that Ashley's parents were loving, educated, and committed to caring for Ashley in their

15. See Gunther & Diekema, *supra* note 1, at 1014; Ashley's Blog, *supra* note 10.

16. Gunther & Diekema, *supra* note 1, at 1014; Ashley's Blog, *supra* note 10; see Ashley's Mom & Dad, The "Ashley Treatment" for the Wellbeing of "Pillow Angels," <http://pillowangel.org/AT-Summary.pdf> (last visited Apr. 10, 2009) (summarizing Ashley's treatments and their purposes) [hereinafter Treatment Summary].

17. Gunther & Diekema, *supra* note 1, at 1014; Treatment Summary, *supra* note 16.

18. Gunther & Diekema, *supra* note 1, at 1014; Treatment Summary, *supra* note 16.

19. See Treatment Summary, *supra* note 16.

20. Gunther & Diekema, *supra* note 1, at 1015; Treatment Summary, *supra* note 16.

21. Treatment Summary, *supra* note 16.

22. *Id.*

23. Gunther & Diekema, *supra* note 1, at 1014.

home.²⁴ The committee concluded that the procedure was in the patient's best interest because it would "improve her quality of life, facilitate home care, and avoid institutionalization in the foreseeable future."²⁵ The committee informed Ashley's parents that prior to the procedures, they should obtain legal advice to ensure that the hysterectomy complied with Washington State requirements for sterilization of women or girls who could not consent to the procedure.²⁶ The parents' attorney, who specialized in disability law, advised them that because the procedure was not being performed primarily for the purpose of sterilization, a court order was not needed to perform the treatments.²⁷ Relying on this advice, the doctors performed the procedures without obtaining a court order.²⁸

After the medical journal article was published and the public reacted passionately, the girl's parents created a blog about their daughter, whom they identified only as Ashley, so they could explain their treatment decisions.²⁹ They named the procedures the "Ashley Treatment."³⁰ Ashley's story made headlines around the world, igniting strong emotional reactions and a divisive debate regarding bioethics, the rights of disabled children and adults, autonomy, the role of medicine, and who should be able to make these decisions.³¹ Those weighing in on the debate included ethicists, doctors, disability advocates, disabled adults, and families of children

24. ETHICS COMMITTEE MEETING, *supra* note 11, at 2.

25. *Id.* at 3.

26. *Id.* at 2.

27. LETTER, *supra* note 5.

28. DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROT. & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 1 (2007), available at <http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment.pdf> [hereinafter INVESTIGATIVE REPORT].

29. See Ashley's Blog, *supra* note 10.

30. Treatment Summary, *supra* note 16.

31. E.g. Catherine Elsworth, *Why We Will Never Let Our Girl Grow Up*, DAILY TELEGRAPH (UK), Jan. 4, 2007, at 15; Sam Howe Verhovek, *Parents Halt Growth of Severely Disabled Girl*, SEATTLE TIMES, Jan. 4, 2007, at A1; *Larry King Live* (CNN television broadcast Jan. 12, 2007), transcript available at <http://transcripts.cnn.com/TRANSCRIPTS/0701/12/lkl.01.html>; *Decision to Stunt Growth of Disabled Girl Triggers Debate* (Australian Broadcasting Corporation television broadcast Jan. 4, 2007).

and adults with conditions similar to Ashley's.³² Ashley's parents informed Larry King that as of January 12, 2007, they had received over 3,600 private messages, ninety percent of which supported the treatment.³³ A number of parents of profoundly disabled children wrote that they would want or were currently pursuing the Ashley Treatment for their children.³⁴

The publicity reached disability-advocate groups, which alerted the Washington Protection and Advocacy System (WPAS), the Washington agency federally authorized to investigate incidents of abuse or neglect of individuals with disabilities.³⁵ The family's attorney wrote that prior Washington cases regarding sterilization petitions were not controlling because they were distinguishable based on the differences in the mental ability of the girls involved and the purpose of the procedure.³⁶ The WPAS, however, concluded that these cases were controlling, and because the hysterectomy was performed without a court proceeding,

32. Compare Peter Singer, Op-Ed., *A Convenient Truth*, N.Y. TIMES, Jan. 26, 2007, Late Edition (East Coast), at A21 (arguing that it is ethical for children with disabilities such as Ashley's to receive this treatment), and Lainie Friedman Ross, *Growth Attenuation by Commission and Omission May Be Ethically Justifiable in Children with Profound Disabilities*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 418 (2007), with Wesley J. Smith, *An Ethically Unsound "Therapy"*, NAT'L REV. ONLINE, Feb. 8, 2007, <http://article.nationalreview.com/?q=NTNhNDzAzMzQxM2YwZjkwMjMxZGY4Y2FiNDRjZTFkMjM=> (arguing that the treatment is unethical and should not be allowed), and Hank Bersani, *Unjustifiable Non-Therapy*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 520, 521 (2007).

33. *Larry King Live*, *supra* note 31. The parents provided this information by email and have not revealed their identities.

34. The "Ashley Treatment," Testimonies from Other Families or Practitioners, Jan. 8, 2007, http://ashleytreatment.spaces.live.com/mmm2008-07-24_12.50/blog/cns!E25811FD0AF7C45C!1826.entry [hereinafter Testimonials]; see *The Humbling True Story of Why This Mother Wants Her Disabled Daughter to Have Her Womb Removed*, MAIL ONLINE, Oct. 12, 2007, <http://www.dailymail.co.uk/femail/article-487155/The-humbling-true-story-mother-wants-disabled-daughter-womb-removed.html> [hereinafter *Humbling True Story*].

35. INVESTIGATIVE REPORT, *supra* note 28, at 5; see also The Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e (1973); Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 (2000); WASH. REV. CODE ANN. § 71A.10.080 (West 2008).

36. LETTER, *supra* note 5, at 4.

including representation by a guardian *ad litem* and a court order authorizing the procedure, Ashley's constitutional rights had been violated.³⁷ Their report stated that the treatment violated Ashley's Fourteenth Amendment privacy right to choose to procreate.³⁸ The WPAS also stated that because the growth attenuation therapy and breast bud removal were invasive and irreversible medical procedures, they should not have been performed without a court order.³⁹

In response to the situation, Children's Hospital organized a symposium to discuss the issue of growth attenuation therapy in profoundly developmentally disabled children at the University of Washington School of Law.⁴⁰ The event was designed to provide a forum in which bioethicists, members of the hospital ethics committee, members of the disability community, attorneys, and physicians could discuss the role and limits of parental decision-making, the appropriate response of health care professionals, and the views of the disability community in these situations.⁴¹ As a result of the symposium, a working panel was formed. The working panel issued a report of its initial work attempting to find areas of consensus among stakeholders and identify areas of continued disagreement for further discussion on January 23, 2009.⁴²

B. RELEVANT CASE LAW ON STERILIZATION.

State case law regarding sterilization stems from the United States Supreme Court's decision in *Buck v. Bell* to uphold a Virginia statute that authorized the superintendent of

37. INVESTIGATIVE REPORT, *supra* note 28, at 27.

38. *Id.* at 16, 23.

39. *Id.* at 24.

40. Treuman Katz Center for Pediatric Bioethics, The Ethical and Policy Implications of Limiting Growth in Children with Severe Disabilities, http://bioethics.seattlechildrens.org/events/the_ethical_and_policy_implications_of_limiting_growth_in_children_with_severe_disabilities.asp (last visited Apr. 10, 2009).

41. *Id.*

42. Treuman Katz for Pediatric Bioethics, Evaluating Growth Attenuation in Children with Profound Disabilities: Interests of the Child, Family Decision-Making and Community Concerns, http://bioethics.seattlechildrens.org/events/the_ethical_and_policy_implications_of_limiting_growth_in_children_with_severe_disabilities_2009.asp (last visited Apr. 10, 2009).

institutions to decide whether inmates should be sterilized.⁴³ The Court's position was summarized in its infamous statement that "[t]hree generations of imbeciles are enough."⁴⁴ In time, the judicial tide changed: *Skinner v. Oklahoma* held that the right to procreate was a fundamental liberty interest protected by the Fourteenth Amendment of the United States Constitution.⁴⁵ After this, the fundamental right to procreate, and to choose not to procreate, was addressed in cases involving contraception and abortion. In each of these, the Court affirmed that decisions regarding procreation were included in a "zone of privacy" created by the Bill of Rights and incorporated into state law through the Fourteenth Amendment.⁴⁶ State court decisions regarding sterilization petitions by the parents and guardians of developmentally disabled individuals have been addressed through the standards developed in these cases.⁴⁷

In Washington, where Ashley was treated, the controlling cases on sterilization petitions are *In re Guardianship of Hayes*⁴⁸ and *In re Guardianship of K.M.*⁴⁹ In *Hayes*, the mother of a sixteen-year-old girl, whose cognitive ability was at the level of a four or five-year-old, wanted to have her sexually-

43. *Buck v. Bell*, 274 U.S. 200, 208 (1927); see generally Maura McIntyre, Note, *Buck v. Bell and Beyond: A Revised Standard to Evaluate the Best Interests of the Mentally Disabled in the Sterilization Context*, 2007 U. ILL. L. REV. 1303 (2007) (analyzing approaches courts have taken when deciding on sterilization petitions).

44. *Buck*, 274 U.S. at 207.

45. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942) (striking down an Oklahoma law compelling sterilization for classes of criminals as unconstitutionally restricting fundamental liberty interests and violating the Equal Protection Clause of the Fourteenth Amendment).

46. See, e.g., *Roe v. Wade*, 410 U.S. 113, 153 (1973) (holding that the "right of privacy . . . is broad enough to encompass a woman's decision whether or not to terminate her pregnancy"); *Eisenstadt v. Baird*, 405 U.S. 438, 485-86 (1972) (stating that *Griswold's* holding applied to individuals, as well as married couples); *Griswold v. Connecticut*, 381 U.S. 479, 484-85 (1965) (invalidating a Connecticut law which criminalized the use or distribution of contraception).

47. See Roberta Cepko, *Involuntary Sterilization of Mentally Disabled*, 8 BERKELEY WOMEN'S L.J. 122, 137 (1993) (discussing relevant state court decisions).

48. *In re Guardianship of Hayes*, 608 P.2d 635 (Wash. 1980) (en banc).

49. *In re Guardianship of K.M.*, 816 P.2d 71 (Wash. Ct. App. 1991).

active daughter surgically sterilized to prevent pregnancy.⁵⁰ After discussing the history of eugenic sterilization statutes,⁵¹ the court held that because sterilization impacts an individual's fundamental rights of privacy and procreation, there is a "heavy presumption against sterilization of an individual incapable of informed consent that must be overcome by the person or entity requesting sterilization."⁵²

The *Hayes* court described the way in which sterilization petitions must proceed in Washington: the decision must be made in a superior court proceeding in which, using a clear, cogent, and convincing standard, the court finds that: (1) a disinterested guardian *ad litem* represents the incompetent individual's interests; (2) the court receives independent medical, psychological, and social evaluations; (3) the court hears and considers the individual's views as much as possible; (4) the individual is incapable of making her own decision about sterilization and is unlikely to be able to in the foreseeable future; (5) the individual has a need for contraception, including findings that the individual is physically capable of procreation, likely to engage in sexual activity that is likely to lead to pregnancy in the near future, and is permanently incapable of caring for a child, even with reasonable assistance; and (6) that there are no alternatives to sterilization, other contraceptive measures have proved unworkable, the proposed sterilization is the least invasive option, a reversible or "less drastic" option will not be available soon, and there is not an impending advance in the treatment of the individual's disability.⁵³

Hayes was affirmed by the Washington Supreme Court in *K.M.*, when a court order to allow sterilization was overruled because the guardian *ad litem* did not advocate vigorously on behalf of the individual she was representing and the individual's attendance at trial was waived for half of the proceeding.⁵⁴ The *K.M.* court based this opinion on the "gravity

50. *Hayes*, 608 P.2d at 638.

51. *Id.* at 639 (describing the theory that mental illness, mental retardation, criminal behavior, and diseases were hereditary and preventing procreation by individuals afflicted with these problems would reduce the prevalence of these problems in society); *see also* Buck v. Bell, 274 U.S. 200, 200 (1927).

52. *Hayes*, 608 P.2d at 639-41.

53. *Id.* at 641.

54. *In re* Guardianship of *K.M.*, 816 P.2d 71, 74 (Wash. Ct. App.

and finality” of sterilization.⁵⁵

Courts in other states have addressed these issues with varying approaches. The year after *Hayes*, the New Jersey Supreme Court addressed the issue in *In re Grady*, when it upheld a sterilization petition brought by the parents of a nineteen-year-old woman with Down’s syndrome.⁵⁶ The court found that there was also a right to be sterilized within the privacy rights related to contraception and procreation, “[a] decision to be sterilized is also a part of an individual’s right to control her own body and life. . . . Therefore, the right to be sterilized is included in the privacy rights protected by the federal Constitution.”⁵⁷

In *Wentzel v. Montgomery General Hospital, Inc.*, the Maryland Court of Appeals required clear and convincing evidence to show that sterilization is in the best interest of the individual, but allowed courts somewhat more discretion to consider the relative weight of factors in making these decisions.⁵⁸ The court then denied the petition of the guardians of a blind, neurologically impaired thirteen-year-old girl with an IQ of twenty-five to thirty, and the mental capacity of a one or two-year-old child.⁵⁹ The guardians had petitioned to have a hysterectomy performed to address the girl’s pain, hygiene, and contraceptive issues.⁶⁰

While most courts limited the situations in which parents and guardians could request sterilization for those in their care, the California Supreme Court held that the right to make this choice on behalf of their conservatees could not be statutorily eliminated.⁶¹ The statute at issue in *Valerie N.*, was one that denied courts the authority to grant a conservator the power to consent to sterilization on behalf of the severely

1991).

55. *Id.*

56. *In re Grady*, 426 A.2d 467, 486 (N.J. 1981).

57. *Id.* at 474.

58. *Wentzel v. Montgomery General Hosp., Inc.*, 447 A.2d 1244, 1253–54 (Md. 1982); see generally John Handy Culver III, *Wentzel v. Montgomery General Hospital—Maryland’s Equitable Jurisdiction over Sterilization Petitions: A Constitutional Analysis*, 42 MD. L. REV. 549, 569 (1983) (arguing that the standard used by the *Wentzel* court allowed courts too much discretion).

59. *Wentzel*, 447 A.2d at 1255.

60. *Id.*

61. *Conservatorship of Valerie N.*, 40 Cal. 3d 143, 168 (Cal. 1985).

developmentally disabled conservatee, even in cases in which no less “intrusive method” of contraception was available. The California Supreme Court found the statute unconstitutional because it was “constitutionally overbroad.”⁶²

C. APPROACHES TO SURROGATE DECISIONS REGARDING CONSTITUTIONAL RIGHTS.

Decisions on sterilization petitions, for those who are unable to give legal consent, use one of four standards: (1) “mandatory criteria,” where courts authorize sterilization only where specified findings are made; (2) “discretionary best interest,” where courts must evaluate designated criteria to determine if sterilization is in the best interest of the incompetent person; (3) “substituted judgment,” where criteria are used that presumably allow the court to make the decision the incompetent person would have made for herself; and (4) statutes prohibiting sterilization if the candidate for the procedure is unable to provide informed consent.⁶³ *Hayes* is an example of a mandatory criteria decision.⁶⁴

Substituted judgment is used when a person who was competent to make a decision is no longer able to make this decision for herself, and a court or guardian makes the decision based on what the person would have wanted⁶⁵ or, alternatively, based on what most people in that situation would want.⁶⁶ For example, in *In re Quinlan*, the New Jersey Supreme Court held that the only “practical way” for twenty-one-year-old Karen Quinlan, who was in a persistent vegetative state following a drug overdose, to exercise her privacy rights

62. *Id.*

63. George P. Smith II, *Limitations on Reproductive Autonomy for the Mentally Handicapped*, 4 J. CONTEMP. HEALTH L. & POL'Y 71, 81 (1988) (citing Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 807 (1986)).

64. See Smith, *supra* note 63, at 79.

65. See Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37, 37 (2004) [hereinafter Cantor I]. This doctrine was first used in English common law to make decisions for individuals formerly competent to make decisions. Louise Harmon, *Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 34-55 (1990) (describing the history of the doctrine of substituted judgment).

66. Norman L. Cantor, *The Bane of Surrogate Decision-Making Defining the Best Interests of Never-Competent Persons*, 26 J. LEGAL MED. 155, 157 (2005) [hereinafter Cantor II].

to choose whether to continue the use of a respirator was to allow her parents to substitute their judgment for hers.⁶⁷ The court allowed them to do so, even though Karen had not made a legally admissible statement of what she would have wanted in that situation.⁶⁸

In *In re Jobes*, the court stated that its role in cases involving termination of life support was not to decide what should happen to the patient, but “. . . to establish for those who make that decision criteria that respect the right to self-determination and yet protect incompetent patients.”⁶⁹ The court went on to hold that while the court could not determine by clear and convincing evidence what the woman in a vegetative state would have wanted, it would defer the decision to her family’s substituted judgment.⁷⁰ The court reasoned that families are in the best position to decide what is in the person’s best interest.⁷¹ This case illustrates the difficulty of distinguishing the substituted judgment from the best interest standard. For the profoundly developmentally disabled, the substituted judgment standard is actually a best interest standard, because the decision-maker cannot know what the person would have wanted, so instead makes a best interest determination.⁷²

In *Strunk v. Strunk* the Kentucky Supreme Court used a substituted judgment standard for someone who had never been capable of making his own decisions.⁷³ Jerry Strunk was an institutionalized, twenty-seven-year-old man with an IQ of thirty five, a mental age of six, and a close relationship with his twenty-eight-year-old brother who was dying of kidney failure.⁷⁴ Strunk’s mother petitioned the court to allow Jerry to donate a kidney to his brother, and the court analyzed what would be in Strunk’s best interest by using its substituted judgment before allowing the donation.⁷⁵

67. *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).

68. *Id.* at 653.

69. *In re Jobes*, 529 A.2d 434, 437–38 (N.J. 1987).

70. *Id.* at 443.

71. *Id.* at 447–48.

72. See Cantor II, *supra* note 66, at 158.

73. *Strunk v. Strunk*, 445 S.W.2d 145, 148 (Ky. 1969); Harmon, *supra* note 65, at 34–35.

74. *Strunk*, 445 S.W.2d at 146.

75. *Id.* at 149.

Due to the impossibility of separating the two standards for those who have always been profoundly developmentally disabled, many courts have abandoned substituted judgment in favor of a best interest standard.⁷⁶ Some have criticized the idea of using either standard, because they feel the potential for abuse and decisions made based on negative stereotypes of the disabled outweighs the advantages of allowing the decisions to be made.⁷⁷

Professor John Garvey suggests several ways for the state to protect the rights of those who are unable to exercise their right to make constitutionally protected decisions, and argues that which should be used depends on the permanency and severity of the person's disability.⁷⁸ Garvey argues that if the state wants to protect the constitutional freedoms of those who are not, have not, and will never be able to make decisions due to profound cognitive disability, it should allow surrogate decision-makers to exercise these rights on their behalf.⁷⁹

In addition to the right to make choices regarding privacy and procreation, those incapable of making decisions are unable to exercise their Fourteenth Amendment rights to maintain human dignity and avoid severe pain. In *Washington v. Glucksberg*, the United States Supreme Court emphasized the importance of protecting these rights for those unable to exercise them for themselves.⁸⁰ "Avoiding intolerable pain and the indignity of living one's final days incapacitated and in agony is certainly '[a]t the heart of [the] liberty . . . to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life.'"⁸¹

State court cases have addressed these issues. In *Superintendent of Belchertown State School v. Saikewicz*, the Massachusetts Supreme Court held that an institutionalized, elderly man with the mental ability of a two-year-old had a

76. *Id.*

77. See Cantor I, *supra* note 65, at 42–43.

78. John H. Garvey, *Freedom and Choice in Constitutional Law*, 94 HARV. L. REV. 1756, 1762 (1981) (describing "conceptions of . . . laissez faire. . . [i]nstrumental. . . surrogate choices. . . [and situations where] the state has a duty to act in their interests. . .").

79. *Id.* at 1778.

80. *Washington v. Glucksberg*, 521 U.S. 702, 745 (1997).

81. *Id.* (quoting *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 851 (1992)).

dignity interest in not having chemotherapy performed.⁸² The court reasoned that since most people are able to endure the debilitating side effects of chemotherapy because they understand its purpose, the pain from the treatment would be unbearable for Saikewicz, who would not have this understanding.⁸³ Therefore, the court stated that it had made a substituted judgment on his behalf to forego the chemotherapy.⁸⁴

D. THE ROLE OF STATE STATUTES.

In *Cruzan v. Director, Missouri Department of Health*, the United States Supreme Court upheld a Missouri statute requiring clear and convincing evidence of an incompetent patient's prior wish to have life support terminated in a case where the parents of a woman in a chronic vegetative state sought to terminate her life support.⁸⁵ The Court clarified that its holding meant only that the Constitution did not prohibit this procedural requirement, not that states were required to use this standard.⁸⁶

Other states have used this ability to pass statutes that specify procedures for termination of life support. In *Conservatorship of Drabick*, the California Court of Appeals held that a state probate statute permitted a conservator to choose to remove a feeding tube from their conservatee when the decision was made in good faith, based on medical advice, and in the best interest of the conservatee.⁸⁷ The court stated that the constitutional rights of those unable to make these decisions for themselves were best served by allowing conservators to make these decisions based on the

82. Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 428 (Mass. 1977).

83. *Id.* at 432.

84. *Id.*

85. *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 282 (1990); see generally Carl Hernandez III, Note, *Legitimate Exercise of Parens Patriae Doctrine: State Power to Determine an Incompetent Individual's "Right to Die" After Cruzan ex. rel. Cruzan v. Director, Missouri Department of Health*, 6 BYU J. PUB. L. 167, 168 (1992) (arguing that the *Cruzan* case was correctly decided and promoting the use of state *parens patriae* power).

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

87. *Conservatorship of Drabick*, 200 Cal. App. 3d 185, 200 (Cal. Ct. App. 1988).

conservators' particular interests rather than a set of technical standards.⁸⁸

In *In re Guardianship of Hamlin*, the Washington Supreme Court held that a state statute that granted guardians authority to "care for and maintain the incompetent or disabled person, assert his or her rights and best interests, and provide timely, informed consent to necessary medical procedures" meant that a guardian was authorized to make a decision to terminate life support.⁸⁹ The court then laid out guidelines for how this could be done,⁹⁰ but ultimately called on the state legislature to create a statute specific to these situations.⁹¹

E. THE RIGHTS OF PARENTS.

Parental requests to have these treatments performed on their children also raise issues of the constitutional rights of parents to make decisions regarding their children. The right of parents to make decisions regarding how to raise their children has been held to be a fundamental right, although subject to limitations.⁹² Examples include the right of parents to decide whether their children should study a foreign language⁹³ and whether their child should attend public or private school.⁹⁴ The right of parents to make medical decisions for their children has been upheld in cases involving statutes requiring parental consent for minors to obtain abortions.⁹⁵ State courts have also upheld the right of parents to make decisions regarding medical treatment based on the parents' religious beliefs.⁹⁶

88. *Id.* at 208–09.

89. *In re Guardianship of Hamlin* 689 P.2d 1372, 1375 (Wash. 1984) (citing WASH. REV. CODE ANN. § 11.92.040 (West 1990)).

90. *Id.* at 1378–79. The court held that the decision should be made between the guardian, families, physician, and hospital, with court intervention if there was a disagreement between the parties. *Id.*

91. *Id.* at 1379.

92. See *Ginsberg v. New York*, 390 U.S. 629, 639 (1968) (quoting *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944)) (stating that the Supreme Court has consistently held that it is a fundamental right of parents to make decisions for their children).

93. *Meyer v. Nebraska*, 262 U.S. 390, 403 (1923).

94. *Pierce v. Soc'y of the Sisters of the Holy Names of Jesus & Mary*, 268 U.S. 510, 534–35 (1925).

95. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 839 (1992).

96. *Newmark v. Williams*, 588 A.2d 1108, 1111 (Del. 1991); *In re*

II. ANALYSIS

A. BALANCING THE RIGHTS OF PROFOUNDLY DISABLED CHILDREN.

In its report, the WPAS cited *Hayes* as holding that “. . . unlike other medical procedures, parental consent is inadequate in cases involving sterilization.”⁹⁷ The report goes on to say that the breast bud removal and hormone treatment aspects of the Ashley Treatment also infringed on Ashley’s liberty interests and should not have been performed without court approval and representation by a guardian *ad litem*.⁹⁸ The report does not say what standard of review the court should have used in making decisions regarding breast bud removal and hormone treatment.⁹⁹

Had Ashley’s parents sought judicial approval, it is unlikely that they would have overcome the “heavy presumption against sterilization”¹⁰⁰ and been granted a court order allowing the hysterectomy. While they would likely have been able to satisfy some of the mandatory criteria, Ashley’s parents would not have been able to show, by clear, cogent, and convincing evidence that Ashley needed contraception and was likely to engage in sexual activity that was likely to lead to pregnancy because Ashley is not capable of voluntary sexual intercourse. Nor would they be able to show that there were no alternatives to sterilization, that other contraception had not worked, and that this was the least invasive method of contraception. Like the court in *Wentzel*,¹⁰¹ it is unlikely that a Washington court would have found that the proposed procedure was warranted to address menstrual pain.

B. THE HAYES STANDARD IS INAPPROPRIATE FOR THE ASHLEY TREATMENT.

The *Hayes* standard is not appropriate for all decisions to

Green, 448 Pa. 338, 348 (Pa. 1972).

97. INVESTIGATIVE REPORT, *supra* note 28, at 19 (citing *In re Guardianship of Hayes*, 608 P.2d 635, 640 (Wash. 1980) (en banc)).

98. INVESTIGATIVE REPORT, *supra* note 28, at 24.

99. *Id.*

100. *In re Guardianship of Hayes*, 608 P.2d 635, 641 (Wash. 1980) (en banc).

101. *Wentzel v. Montgomery General Hosp., Inc.*, 447 A.2d 1244, 1255 (Md. 1982); *see also* Smith, *supra* note 63, at 81.

perform medical treatments resulting in sterilization of those who are unable to consent to the procedures. While the proposed treatments for Hayes, K.M., and Ashley all resulted in sterilization, Hayes and K.M. were differently situated than Ashley and others with profound neurologic and cognitive disabilities. Hayes and K.M. were able to walk, talk, and discuss issues of parenting, even if their comprehension of the issues was limited.¹⁰² Hayes and K.M. had IQs two to three times greater than what Ashley would be expected to score on an IQ test.¹⁰³ Their mental abilities were similar to those of a four to five and a six to seven-year-old, while Ashley's is that of an infant.¹⁰⁴

Hayes and K.M. were teenagers, whose parents believed them to be sexually active, and the procedures were requested to prevent pregnancy.¹⁰⁵ It is logical to focus on protecting the choice to procreate for those who could voluntarily—even if without complete understanding—exercise that right. This is not analogous to those who are so profoundly disabled that the only way they could procreate would be through sexual assault. Children with profound neurological and cognitive disabilities will never feed themselves, have a conversation, or understand concepts such as becoming a parent—they will require care for all of their needs their entire lives. Someone in that situation cannot exercise their choice to procreate whether or not they have the physical ability to get pregnant.

By focusing on procreation, the *Hayes* standard protects a right that is not actually available to these children, while failing to adequately protect rights that the children could exercise through the decisions of their surrogates. As a result, these children are not able to exercise other fundamental rights, such as dignity, freedom from pain, and life. Availing themselves of these rights could have a meaningful impact on their existence, through greater mobility and contact with family members, less pain, and improved health.

If the *Hayes* standard were a statute, it would not be narrowly tailored to the state's interests, as is required of a

102. *Hayes*, 608 P.2d at 637; *In re Guardianship of K.M.*, 816 P.2d 71, 72–73 (Wash. Ct. App. 1991); LETTER, *supra* note 5, at 2.

103. LETTER, *supra* note 5, at 2.

104. *Hayes*, 608 P.2d at 637; *K.M.*, 816 P.2d at 72–73; Gunther & Diekema, *supra* note 1, at 1014.

105. *Hayes*, 608 P.2d at 637; *K.M.*, 816 P.2d at 72–73; LETTER, *supra* note 5, at 2.

statute affecting individuals' fundamental rights.¹⁰⁶ To be narrowly tailored, a law cannot be under-inclusive or over-inclusive, and must be the least restrictive means available.¹⁰⁷ The *Hayes* standard would be under-inclusive because it focuses on one aspect of the treatment while ignoring the fundamental liberty interests involved in the other aspects of the treatments. The law would also be over-inclusive because it attempts to analyze all medical procedures which result in sterilization by one standard that is tailored to address requests for medical procedures for contraceptive purposes. It would also be over-inclusive in its applicability to people with a wide range of disability levels. Therefore, the standard's mandatory criteria are overly restrictive.

The *Hayes* standard contrasts with the approach used in Canada, where more deference is given to parent or guardian requests for "therapeutic reasons" than for contraceptive reasons.¹⁰⁸ This approach is more appropriate because it emphasizes the candidate's holistic needs and how all the costs and benefits of a procedure would affect her, rather than placing an undue emphasis on the right to choose whether to procreate. For those who are profoundly cognitively and neurologically disabled, the Canadian approach is better suited to the fact that they will never be able to exercise a choice to procreate, but through their surrogate can exercise the rights of life, dignity, and avoiding pain.

C. ALTERNATIVE APPROACHES TO BETTER PROTECTING COMPETING FUNDAMENTAL RIGHTS.

Garvey also advocates interpreting the "life" of the "life, liberty, and property" rights protected in the Constitution expansively, so that the life protected is a "life worth living."¹⁰⁹ This distinction becomes critical in cases involving medical decisions for those unable to provide informed consent. The

106. See *Zablocki v. Redhail*, 434 U.S. 374, 388 (1978) ("When a statutory classification significantly interferes with the exercise of a fundamental right, it cannot be upheld unless it is supported by sufficiently important state interests and is closely tailored to effectuate those results.").

107. See *Burlington Northern R.R. Co. v. Ford*, 504 U.S. 648, 653 (1992).

108. Smith, *supra* note 63, at 82-83.

109. Garvey, *supra* note 78, at 1785-86.

reasons Ashley's parents wanted the procedures performed was to make Ashley's life more "worth living" by increasing the likelihood that she could remain with her family and experiencing greater mobility, better health, and less pain.¹¹⁰ Because what is "worth living" depends on the specifics of a given situation, cases addressing these issues have contextualized which rights should be emphasized and how severe pain must be before its avoidance becomes a constitutional right based on the circumstances of the parties involved.

The issue of how to weigh the rights to avoid severe pain and bodily invasion against the intangible aspects of connection to family and life itself played a role in *Glucksberg*, *Saikewicz*, and *Strunk*.¹¹¹ In *Glucksberg* and *Saikewicz*, the courts weighed the value of living in severe pain against the value of simply being alive and found that the right to avoid pain and live in dignity could, in some circumstances, outweigh the ability to be kept alive.¹¹² In *Saikewicz*, the court held that the deciding factor in the choice of whether to allow the chemotherapy to be withheld was that it would be too much pain to endure for someone who could not understand the cause of the pain.¹¹³ While menstrual pain might not normally be held severe enough that its avoidance is a constitutionally protected right,¹¹⁴ it may in fact be for someone unable to comprehend this recurring and often severe pain, particularly when combined with bed sores, chafing straps, and scoliosis.

In *Strunk* the court held that the value of saving the life of Strunk's brother, to whom Strunk was deeply attached,

110. Gunther & Diekema, *supra* note 1, at 1014; Ashley's Blog, *supra* note 10.

111. *Washington v. Glucksberg*, 521 U.S. 702, 745 (1997); *Strunk v. Strunk*, 445 S.W.2d 145, 147 (Ky. 1969); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 420, 432 (Mass. 1976).

112. *Glucksberg*, 521 U.S. at 745; *Saikewicz*, 370 N.E.2d at 432.

113. *Saikewicz*, 370 N.E.2d at 432 (holding that the probate judge's use of "quality of life" should be understood as a reference to a continued state of pain and disorientation due to chemotherapy; the *Saikewicz* court chose to balance this "quality of life" against the possibility of remission and affirmed the decision to withhold treatment).

114. See *supra* note 81 and accompanying text. Cases have held that "avoiding the difficulties or inconveniences" of menstrual hygiene cannot be considered in a decision to sterilize someone incompetent to consent. Smith, *supra* note 63, at 81.

outweighed the pain and bodily invasion of an organ removal and donation.¹¹⁵ Similar to the intangible worth of Saikewicz having his brother in his life, the intangible benefits to Ashley of living at home with her family, experiencing greater physical contact and mobility, better health, and more frequent and varied outings outweigh the costs of surgery, organ removal, and loss of the physical ability to procreate. Emphasizing the more concrete, but less applicable, right to choose procreation shortchanges the importance of these intangible benefits.

D. PARENTS SHOULD BE ABLE TO MAKE THESE DECISIONS ON THEIR CHILDREN'S BEHALF.

As the *Quinlan* and *Grady* courts and Professor Norman Cantor suggest, without the ability of surrogates to make decisions on their behalf, those who have never been competent to decide have no way to exercise these constitutional rights.¹¹⁶ Those closest to the person are in the best position to decide which, and in what manner, these rights should be exercised. In her *Cruzan* concurrence, Justice O'Connor addressed the importance of allowing those closest to someone who cannot make decisions to make those decisions on their behalf: "In my view, such a duty may well be constitutionally required to protect the patient's liberty interest. . . ."¹¹⁷

The primary reason that Ashley's parents requested these treatments was to increase her chances of continuing to live at home and have greater interaction with parents, siblings, and the world outside her home.¹¹⁸ Ashley's favorite activities would likely be diminished if she grew to her anticipated size.¹¹⁹ She would need a lift to move her from her bed and her

115. *Strunk*, 445 S.W.2d at 147.

116. *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976); *In re Grady*, 426 A.2d 467, 480-81 (N.J. 1981); Cantor II, *supra* note 66, at 156.

117. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring).

118. Ashley's Blog, *supra* note 10.

119. Gunther & Diekema, *supra* note 1, at 1013. "The American Academy of Pediatrics recently endorsed the goal of Healthy People 2010 to have all children with disabilities out of congregate care facilities and into homes by the year 2010." *Id.* Moving disabled children into homes becomes much harder as the person gets larger: "[t]he difficulties of caring for these children—dressing, bathing, diapering, transferring from bed to wheelchair, transporting—increase exponentially as the children grow to

family would have to replace her usual fleece lined stroller with a wheelchair, which causes her great discomfort.¹²⁰

Cantor suggests that for those who cannot make decisions for themselves, an alternative form of substituted judgment is to consider what a majority of people would do in the same situation.¹²¹ Those closest to nonambulatory, profoundly developmentally disabled children would be in the best position to provide this insight. Ashley's parents received over 1,150 emails from parents and caregivers with direct experience caring for children with similar conditions.¹²² These included: a mother who felt she failed her daughter when she was forced to institutionalize her when she could no longer care for her due to her size, a person whose cousin died from menstrual hygiene issues, a woman who wished she was able to provide this treatment to her now sixteen-year-old daughter, a couple in New Zealand who were investigating the possibility of obtaining these procedures for their daughter, and a nurse whose patient stopped using her crawler because of discomfort caused by her size D breasts.¹²³ Ashley's parents also received emails from dozens of parents considering the treatment for their children.¹²⁴ A British newspaper ran a story about a woman in England who regrets that this treatment was not available when her daughter was younger.¹²⁵ It seems reasonable to use the sentiments of those who are closest to those who are unable to make decisions for themselves—such as the people described above—to determine what the majority of those in the same situation would do. This could then be a basis for a substituted judgment.

One criticism of the Ashley Treatment is that it is a form of eugenics.¹²⁶ This type of criticism, as well as the *Hayes* standard's focus on preserving the right to procreate at the expense of other rights, can be viewed as a backlash to the abuses created during the eugenics movement. But every decision that leads to sterilization of a woman or girl who is unable to consent is not eugenics, and there is no indication

adolescence and adulthood." *Id.*

120. Ashley's Blog, *supra* note 10.

121. Cantor II, *supra* note 66, at 157–58.

122. Ashley's Blog, *supra* note 10.

123. Testimonials, *supra* note 34.

124. Treatment Summary, *supra* note 16.

125. *Humbling True Story*, *supra* note 34.

126. *Larry King Live*, *supra* note 31.

that this was the case for Ashley or would be for others in similar situations. Ashley's parents opted for the treatment because they determined it was in her best interest, not to prevent her from passing on a mental disability. The California Supreme Court in *Valerie N.* acknowledged that sterilization decisions by guardians can be made for appropriate reasons and held that California could not pass a law that prohibited conservators from authorizing sterilization for their conservatees.¹²⁷

A frequent criticism of this treatment has been its potential for abuse and the possibility of using medical treatments to control children who are problematic to their parents. As Princeton bioethicist Peter Singer points out, the large and growing number of children on medication to treat attention deficit disorder poses a greater risk of this than a treatment that is potentially applicable to only a small number of the most profoundly disabled children.¹²⁸ Profoundly developmentally disabled children and their families should not be denied the ability to choose one of the few options available to them because of general concerns of a negative impact on other disabled children in quite different circumstances.

A related criticism is that decisions will be made based on stereotypes. In Ashley's case, the treatment plan was based on her individual needs. Ashley's treatment was not a statement about the relative value of disabled and non-disabled people, whether society feels disabled people should have children, or whether disabled people are capable of doing more than others assume or allow them to do. The fact that many of the disability advocates speaking out on this issue are disabled themselves¹²⁹ illustrates the broad range of abilities and situations among those that are lumped together as "disabled" and the difficulty of making generalizations of what is best for those who are disabled as a group.¹³⁰ The treatment was intended to, and did help, Ashley live the fullest life she could, not to limit her options based on her disability.

127. *Mildred G. v. Valerie N.*, 40 Cal. 3d 143, 168 (Cal. 1985).

128. Singer, *supra* note 32, at A21.

129. *Larry King Live*, *supra* note 31.

130. James. W. Ellis, *Decisions by and for People with Mental Retardation: Balancing Considerations of Autonomy and Protection*, 37 VILL. L. REV. 1779, 1779 (1992).

Decisions on whether to perform this type of treatment should include a consideration of all the constitutional rights at issue, medical prognosis, and the specifics of the person's situation. In *Cruzan*, the Court recognized *Quinlan's* reasoning¹³¹ and stated that ". . . there comes a point at which the individual's rights overcome the State interest [T]he State's interest 'weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims.'"¹³² This statement considers the changing weight of interests as prognosis changes in a terminally-ill patient. It seems reasonable that a similar interest-weighting process should occur for those who have a wide range of disabilities and whose parents or guardians are seeking, in their best interest, a medical treatment resulting in sterilization or other permanent effects. A blanket standard that attempts to address all of these varying prognoses seems likely to produce inappropriate outcomes.

E. PARENTS' RIGHTS TO MAKE DECISIONS REGARDING THEIR CHILDREN.

Parents' ability to make decisions regarding their children has been held to be a fundamental constitutional right;¹³³ the Supreme Court has stated that:

[C]onstitutional interpretation has consistently recognized that the parents' claim to authority in their own household to direct the rearing of their children is basic in the structure of our society. "It is cardinal with us that the custody, care and nurture of the child reside first in the parents"¹³⁴

Requiring parents of nonambulatory, profoundly neurologically and cognitively disabled children to obtain a court order based on criteria that are not tailored to their situation effectively—and inappropriately—eliminates one of the very few options they have available to do what they feel is

131. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 270 (1990).

132. *Id.*

133. *E.g.*, *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 895, 965 (1992); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (stating that the Supreme Court has consistently held that it respects parental privacy and freedom in making choices regarding raising their children); *Pierce v. Soc'y of Sisters of the Holy Names of Jesus & Mary*, 268 U.S. 510, 534 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923); *see supra* notes 92–95 and accompanying text.

134. *Ginsberg v. New York*, 390 U.S. 629, 639 (1968) (quoting *Prince*, 321 U.S. at 166).

in the best interest of their children. While the right of parents to make decisions for their children is not absolute, a number of state cases have addressed the ability to withhold treatment based on their religious beliefs.¹³⁵

In *Newmark v. Williams* the parents of a three-year-old boy with cancer refused chemotherapy for their son due to their religious beliefs and the negative effects of the treatment.¹³⁶ The boy's doctor advocated for the boy to be treated and removed from his family home for the treatment because the doctor believed the family's beliefs would prevent them from providing all the prescribed treatment and care.¹³⁷ The court weighed the prognosis, the effects and likelihood of success of treatment, the importance of the child remaining with his family, and the child's right to life, against the state's interest in the child's life and the parents' right to evaluate the value of attempting to save their child's life compared to letting their child live only a few months—but without the debilitating side effects of the chemotherapy.¹³⁸ The court determined that due to the likely pain of the procedure, the forty percent likelihood of a cure, and the trauma to the boy of being away from his family—none of which he would be able to comprehend—it was in the boy's best interest to remain with his family and forego the treatment.¹³⁹

A similar approach should be used to allow parents of nonambulatory, profoundly neurologically and cognitively impaired children to decide what is in the best interest of their child, with appropriate safeguards for situations in which the parents' purported best interest decisions are made for other reasons or not in the child's best interest. For parents of children who are profoundly disabled, the majority of the decisions they must make for their children are medical ones. This should not limit the parents' constitutional rights to make decisions regarding their children, unless there is reason to believe that, in doing so, they inappropriately infringe on the child's rights. While there may be exceptions, in a majority of

135. See, e.g., *Newmark v. Williams*, 588 A.2d 1108, 1120–21 (Del. 1991); *Muhlenberg Hosp. v. Patterson*, 320 A.2d 518, 521 (N.J. Super. 1974).

136. *Newmark*, 588 A.2d at 1111.

137. *Id.* at 1119.

138. *Id.* at 1117–18.

139. *Id.* at 1120.

circumstances, the family is in the best position to make a decision for its loved one. This should be the presumption, with parents' decision-making ability limited only when there is reason to believe this is not the case. In *Jobes*, the New Jersey Supreme Court stated:

Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort, care, and best interests¹⁴⁰

Garvey argues that in cases protecting the liberties of children, "what the Constitution protects is not a choice that the child has made but one that his parents have determined is beneficial to him."¹⁴¹ For children who are profoundly neurologically and cognitively disabled, the two interests are particularly enmeshed, as the child will never be able to make decisions for herself. Therefore, protecting the rights of parents to make decisions is also a way of protecting the child's only way to express her interests.

F. STATES SHOULD ENACT STATUTES ADDRESSING THESE DECISIONS.

Requiring parents of profoundly neurologically and cognitively disabled children to seek court approval, based on criteria created to address sterilization petitions requested for contraceptive reasons, impermissibly infringes on the constitutional rights of these children and their parents. States should enact legislation specifically addressing these situations. In her *Cruzan* concurrence, Justice O'Connor stated support for state action of this type:

[N]o national consensus has yet emerged on the best solution for this difficult and sensitive problem. Today we decide only that one State's practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the "laboratory" of the States.¹⁴²

Without state legislative action, courts, such as the *Hayes*

140. *In re Jobes*, 529 A.2d 434, 445 (N.J. 1987).

141. Garvey, *supra* note 78, at 1782.

142. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 292 (1990) (O'Connor, J., concurring) (citing *New State Ice Co. v. Liebmann*, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting)).

court, have inappropriately assumed this legislative role.¹⁴³

States should enact statutes which allow parents and guardians of nonambulatory, profoundly neurologically and cognitively disabled children to decide, with their children's doctors, to have this treatment performed if they feel it is in their children's best interest to do so. Safeguards should include the agreement of two doctors and a hospital ethics committee, with recourse to a court if all parties are not in agreement. In a court proceeding, a guardian *ad litem* should represent the child's interest, and the court should use a "best interest" standard to make its determination. This framework addresses the procedures' gravity and permanency by requiring more procedural safeguards than are used in most parental medical decisions. At the same time, it allows most families to have the procedures performed without requiring already heavily-burdened families to obtain legal counsel and justify their position to a court—unless doctors and a hospital ethics committee do not agree with their decision. Cantor argues that the education of surrogates and medical personnel and the use of hospital ethics committees or courts when a treatment used does not fall within "acceptable standards of patient care" provide protection from abuses through these decisions.¹⁴⁴ It is worth noting that this is essentially the process that occurred before Ashley was treated.¹⁴⁵

In his *Cruzan* dissent, Justice Stevens cited the courts in *Saikewicz* and *Drabick* when he stated that respect for those who cannot make decisions for themselves should allow surrogates to make decisions on their behalf by considering that person's best interests.¹⁴⁶ It seems likely that a court would have found Ashley's treatment warranted under a best interests standard; the hospital ethics committee, Ashley's doctors, and her parents decided that this treatment was in Ashley's best interest.¹⁴⁷ A court order to perform the procedure, however, would have been unlikely under the

143. Smith, *supra* note 63, at 79.

144. Cantor I, *supra* note 65, at 70.

145. Gunther & Diekema, *supra* note 1, at 1014.

146. *Cruzan*, 497 U.S. at 349 n.21 (Stevens, J., dissenting) (citing *In re Conservatorship of Drabick*, 245 Cal. Rptr. 840, 861 (Cal. Ct. App. 1988); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977)).

147. ETHICS COMMITTEE MEETING, *supra* note 11, at 3.

Hayes standard, which would have governed at least the hysterectomy portion of the procedure had Ashley's parents gone to court.

A state statute enabling parents of children whose doctors and parents feel that the Ashley Treatment is in the child's best interest to make these decisions would answer the Washington Supreme Court's parallel request in *Hamlin* that state legislatures enact statutes detailing procedures that would allow surrogates to make decisions on whether to terminate life support for patients in persistent vegetative states.¹⁴⁸ This is also consistent with Professor George Smith's argument that families are best able to protect the candidate's best interest, and therefore the family "alone," rather than an "impersonal" court, should make the decision—with the court available to protect the patients' best interest if there is a conflict of interest between the parents and the doctors.¹⁴⁹ Requiring hospital ethics committee approval provides an additional safeguard of these children's rights and interests.

A statute allowing parents of nonambulatory, profoundly neurologically and cognitively disabled children to choose this type of treatment for their child would be narrowly tailored to protect the state's compelling interest in procreation¹⁵⁰ and protecting its citizens from bodily invasion,¹⁵¹ while not infringing on the children's rights to dignity,¹⁵² avoidance of pain,¹⁵³ and life¹⁵⁴ or the parents' right to make decisions regarding the care and well-being of their children.¹⁵⁵ Because there are not mandatory criteria that must be met before the decision to have the procedures performed, a statute of this type would be the least restrictive means available to ensure the competing interests in these situations are adequately protected. The statute would not be under- or over-inclusive, because instead of applying to sterilization decisions made by surrogates for those who are unable to consent regardless of the level of their disability and the reason for the procedure that would result in sterilization, it would apply to a specific

148. *In re Guardianship of Hamlin*, 689 P.2d 1372, 1379 (Wash. 1984).

149. Smith, *supra* note 63, at 88-89.

150. *See supra* note 46 and accompanying text.

151. *See supra* notes 111-14 and accompanying text.

152. *Id.*; *see also supra* notes 82-84 and accompanying text.

153. *See supra* notes 111-14 and accompanying text.

154. *See supra* note 113 and accompanying text.

155. *See supra* notes 92-96 and accompanying text.

type of treatment and to only one to two percent of developmentally disabled children¹⁵⁶ who meet the treatment criteria. Therefore, it is likely that if challenged, the proposed statute would pass the rigors of strict scrutiny review.

III. CONCLUSION

This Note considers the current legal framework applied to a decision made by parents of a nonambulatory, profoundly developmentally disabled girl to have growth attenuation and other associated treatments performed. The Note then analyzes whether this framework adequately protects the best interest and constitutional rights of potential candidates for this treatment and their parents. The Note concludes that it does not. The Note suggests that states should enact statutes that are narrowly tailored to these cases in order to address and protect the multiple rights and interests involved in these situations. These statutes—which should include procedural safeguards—should allow the treatment when parents and doctors agree that it is in the child’s best interest.

156. See *supra* note 8 and accompanying text.