

GROWTH, INTERRUPTED: NONTHERAPEUTIC GROWTH
ATTENUATION, PARENTAL MEDICAL DECISION MAKING,
AND THE PROFOUNDLY DEVELOPMENTALLY DISABLED
CHILD'S RIGHT TO BODILY INTEGRITY

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*Should parents of a profoundly developmentally disabled child be permitted to permanently terminate their child's healthy bodily development in order to arguably increase the child's quality of life? While such a procedure may sound like something out of science fiction, a highly publicized medical journal article released in 2006 described the case of Ashley X, a profoundly developmentally disabled child who received high-dose hormone treatment—along with a mastectomy and a hysterectomy—to permanently stunt her growth and allegedly increase her quality of life. Though the authors of the article presented this type of nontherapeutic growth attenuation as a viable medical option for profoundly disabled children, critics from all over the world characterized the procedure—which came to be known as the “Ashley Treatment”—as a grave and unacceptable human rights violation. Nonetheless, the Ashley Treatment has also been met with support from some, most notably the parents of profoundly disabled children, many of whom have expressed a desire for their own children to undergo similar procedures. This Note explores the question of whether parents should be permitted to choose such interventions on behalf of a child from the perspective of the child's rights, specifically, the child's fundamental right to bodily integrity. Following a brief description of the case of Ashley X and the ensuing controversy, the author describes the right to bodily integrity, including its origins, its modern constitutional status, and its application to profoundly disabled children. The author then discusses the general presumption of parental authority to make medical decisions on behalf of children, and the *parens patriae* power of the courts to intervene in parental medical decision making to protect a child's rights and promote the best interests of the child. Finally, the author applies the preceding*

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analysis to the Ashley Treatment and similar nontherapeutic, growth-attenuating interventions, concluding that judicial review should be invoked whenever a parent seeks this type of intervention on behalf of a child and explaining that a court rigorously applying the best interests standard should rarely, if ever, find nontherapeutic growth attenuation to be in the best interests of the profoundly disabled child, because the magnitude of harm threatened by permanently terminating the child's healthy physical development—thus, severely and irreversibly violating the child's right to bodily integrity—ultimately outweighs any purported benefits.

I. INTRODUCTION

[T]his fully human life requires many things from the world: adequate nutrition, education of the faculties, *protection of bodily integrity* In each case, an intuitive argument must be made that a life without a sufficient level of each of these entitlements is a life so reduced that it is not compatible with human dignity.¹

In October 2006, Drs. Daniel Gunther and Douglas Diekema published an article describing a new medical protocol “developed for the purpose of providing parents the option of preventing their children with developmental disabilities from reaching full adult stature and physical sexual development.”² This article presented the case of a profoundly developmentally disabled six-year-old girl whose parents sought to permanently arrest the child’s growth while she “was still small.”³ To achieve this result, the physicians administered high-dose hormone therapy, which brought about permanent attenuation in the child’s size.⁴ In addition, in response to the parents’ “concerns about the complications of puberty,” the physicians performed a hysterectomy on the child.⁵ Several months later, the child’s parents identified the patient in the article as Ashley.⁶ They also revealed that, in addition to undergoing growth-attenuating hormone therapy and a hysterectomy, Ashley’s undeveloped breast buds were removed in order to “[e]liminate [the potential future] discomfort caused from large breasts.”⁷ The revelation of this unprecedented and radical series of medical interventions sparked worldwide

1. MARTHA C. NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* 278–79 (2006) (emphasis added).

2. DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROT. & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE “ASHLEY TREATMENT” 6–7 (2007), <http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment.pdf>.

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

4. *Id.* at 1013–14.

5. *Id.* at 1014.

6. *Kept Small to Aid Parents*, *NEWSDAY*, Jan. 5, 2007, at A38.

7. See Ashley’s Parents, The “Ashley Treatment” for the Wellbeing of “Pillow Angels,” <http://pillowangel.org/AT-Summary.pdf> [hereinafter Ashley’s Parents, *Flowchart*].

controversy over the ethical implications of the so-called “Ashley Treatment,” and whether such procedures should be an option available to parents of disabled children.⁸ People all over the world spoke out, expressing strong opinions both in favor of and in opposition to the interventions administered to Ashley X.⁹

Although there are compelling emotional arguments on both sides of the debate over the Ashley Treatment, “visceral reactions are not an argument for or against.”¹⁰ Rather, “[g]rowth attenuation treatment for children such as Ashley challenges us to think beyond our initial reactions.”¹¹ Specifically, the debate needs to move beyond emotional, experience-based arguments to the substantive legal question of whether Ashley’s rights were violated.¹²

This Note argues that, by profoundly and irreversibly altering Ashley’s body for social—as opposed to therapeutic—reasons,¹³ Ashley’s constitutionally protected fundamental right to bodily integrity was substantially violated. Although nothing will be able to make Ashley whole, this Note argues that measures should be taken to prevent such violations of the rights of profoundly developmentally disabled children¹⁴ in the future. Rather than simply offering isolated arguments against the Ashley Treatment, this Note attempts to expand on and synthesize various arguments that scholars and critics have raised in response to the Ashley Treatment—namely, the violation of the child’s fundamental right to bodily integrity,¹⁵ the need for judicial review of parental requests for such interventions,¹⁶ and the appropriateness of the best interests

8. *Parents Defy Critics in Blog on Their Disabled Pillow Angel*, NEW ZEALAND HERALD, Jan. 6, 2007, at B10 (noting that Ashley’s case “is stirring worldwide ethical debate”).

9. See Catharine Paddock, *Public Debates Decision to Keep Disabled Girl’s Growth Stunted*, MED. NEWS TODAY, Jan. 5, 2007, <http://www.medicalnewstoday.com/articles/60268.php> (discussing the powerful, emotional reactions to the Ashley Treatment, both for and against).

10. Nancy Gibbs, *Pillow Angel Ethics*, TIME, Jan. 22, 2007, at 56, 57 (quoting Dr. Gunther, one of the aforementioned physicians involved in Ashley’s case).

11. Sarah E. Shannon & Teresa A. Savage, *The Ashley Treatment: Two Viewpoints*, 33 PEDIATRIC NURSING 175, 175 (2007).

12. See CARLSON & DORFMAN, *supra* note 2, at 13.

13. See Alicia R. Ouellette, *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case*, 8 HOUS. J. HEALTH L. & POL’Y 207, 209 (2008) (contending that Ashley’s parents altered Ashley’s body “profoundly and permanently for social, not medical, reasons”).

14. By “profoundly developmentally disabled children,” I am referring to children who “have been profoundly retarded or severely brain damaged since birth” and “whose mental functions are so limited that they cannot make considered choices about important matters affecting their lives.” NORMAN L. CANTOR, MAKING MEDICAL DECISIONS FOR THE PROFOUNDLY MENTALLY DISABLED 1 (2005).

15. Nat’l Council on Indep. Living, 2007 National Council on Independent Living Annual Meeting Resolutions, <http://www.ncil.org/news/2007Resolutions.html> (follow “View the Resolutions” hyperlink) (last visited Nov. 11, 2009).

16. See Ouellette, *supra* note 13, at 241–42; John William McDermott, Note, *Growth Attenuation in the Profoundly Developmentally Disabled: A Therapeutic Option or a Socioeconomic Convenience?*, 32 SETON HALL LEGIS. J. 427, 431 (2008).

standard¹⁷—into one comprehensive, workable legal framework for protecting the rights of children such as Ashley X.

Part II of this Note describes the case of Ashley X and introduces the arguments for and against the medical interventions presented in that case. Part III discusses the fundamental right to bodily integrity, tracing the history of the right from its historic roots to its modern constitutional status. It further argues that this right to bodily integrity fully extends to profoundly developmentally disabled children despite the fact that they are personally unable to exercise the right to self-determination in deciding whether to undergo medical procedures. Part IV focuses on the process of making medical decisions on behalf of profoundly developmentally disabled children. It begins by discussing the rationales behind the typical presumption of parental authority to make medical decisions for their children. Next, it explains the power of the courts to intervene in parental medical decision making under the equitable doctrine of *parens patriae*, and discusses existing categorical exceptions to the parental medical decision-making presumption in which courts routinely intervene to protect the rights of vulnerable child-patients. Part IV concludes by discussing the best interests test, which guides a court's determination of whether to approve a particular medical procedure on behalf of a child. Finally, Part V applies the above analysis to the Ashley Treatment and similar nontherapeutic, growth-attenuating procedures, concluding that nontherapeutic growth attenuation should be recognized as a categorical exception to the general presumption of parental medical decision-making authority. Thus, judicial review should be invoked whenever a parent seeks this type of medical intervention on behalf of a developmentally disabled child. Part V further argues that a court rigorously applying the best interests standard should rarely, if ever, find nontherapeutic growth attenuation to be in the best interests of the profoundly disabled child because the magnitude of harm threatened by permanently terminating the child's healthy physical development—thus, severely and irreversibly violating the child's right to bodily integrity—ultimately outweighs any purported benefits.

II. BACKGROUND: THE CASE OF ASHLEY X

In the October 2006 issue of the *Archives of Pediatrics & Adolescent Medicine*, Drs. Daniel Gunther and Douglas Diekema published an article entitled *Attenuating Growth in Children with Profound Developmental Disability*.¹⁸ The article described the case of a six-year-old girl

17. See Christine Ryan, Note, *Revisiting the Legal Standards That Govern Requests to Sterilize Profoundly Incompetent Children: In Light of the "Ashley Treatment," Is a New Standard Appropriate?*, 77 *FORDHAM L. REV.* 287, 324 (2008).

18. See Gunther & Diekema, *supra* note 3.

diagnosed with static encephalopathy¹⁹ whose condition had not progressed beyond “that of an infant.”²⁰ She could not “sit up, ambulate, or use language”; yet, she “clearly” was able to respond to others by “vocalizing and smiling in response to care and affection.”²¹ Nonetheless, her physicians concluded that the child would experience “no significant future improvement in her cognitive or neurologic baseline.”²²

Her parents, prompted by the fact that the girl was displaying early signs of puberty and accelerated growth, consulted with physicians regarding their concerns for their daughter’s future.²³ The parents were particularly concerned with the “complications of puberty”—especially menstruation—and the prospect that the child’s continued growth might make it difficult to care for her at home.²⁴ In response to these concerns and following “extensive consultation” among the parents and medical personnel, the physicians formulated a plan to limit the child’s growth using a combination of high-dose estrogen treatment and a hysterectomy.²⁵

Due to the unconventional and controversial nature of the proposed treatments, the plan was referred to the hospital’s internal ethics committee for approval.²⁶ Following a “lengthy discussion,” the committee concluded that both requests were “ethically appropriate in this case.”²⁷ Nonetheless, the committee cautioned that the parents did not have legal authority under Washington common law to consent to the sterilization and advised the parents to consult with an attorney.²⁸

In keeping with the directives of the ethics committee, the parents met with Larry Jones, an attorney experienced in “advocating for parents of children with developmental disabilities.”²⁹ Jones concluded that, although Washington courts have held that a court order is necessary to

19. The National Institute of Neurological Disorders and Stroke defines encephalopathy as a term used to describe any “disease of the brain that alters brain function or structure.” NINDS Encephalopathy Information Page, <http://www.ninds.nih.gov/disorders/encephalopathy> (last visited Nov. 11, 2009). The term “static encephalopathy” is used to describe a nonprogressive form of encephalopathy. JOSÉ BILLER, *PRACTICAL NEUROLOGY* 407 (2d ed. 2002). In other words, “[t]he diagnosis means that her brain has been damaged and the addition of the term ‘static’ means that her condition will not improve.” Peter A. Clark & Lauren Vasta, *The Ashley Treatment: An Ethical Analysis*, 5 *INTERNET J.L. HEALTHCARE & ETHICS* (2007), http://www.ispub.com/journal/the_internet_journal_of_law_healthcare_and_ethics/_volume_5_number_1_45/article/the_ashley_treatment_an_ethical_analysis.html (citation omitted).

20. See Gunther & Diekema, *supra* note 3, at 1014.

21. *Id.*

22. *Id.*

23. *Id.*

24. *Id.*

25. *Id.*

26. *Id.* The Seattle Children’s Hospital Ethics Committee, “comprised of a multi disciplinary group of providers and community members with training in medical ethics and one of Children’s Hospital’s lawyers,” exists to provide “non-binding recommendations to practitioners and family members looking for guidance regarding procedures or practices that appear to raise ethical concerns.” CARLSON & DORFMAN, *supra* note 2, at 13.

27. Gunther & Diekema, *supra* note 3, at 1014. This meeting reportedly lasted “for over an hour.” Ouellette, *supra* note 13, at 213 (citation omitted).

28. CARLSON & DORFMAN, *supra* note 2, at 13.

29. *Id.* at 14.

proceed with sterilization of a cognitively disabled child, no court order was necessary in this case.³⁰ Jones reasoned that “because sterilization was not the sole purpose of the treatment, there is an exception to the rule.”³¹

Both the parents and the physicians relied upon Jones’ opinion, and proceeded with the procedures as planned without a court order.³² The surgical procedures and administration of high-dose hormone therapy proved “uneventful” and, as of the time Gunther and Diekema’s article was published, the child was said to be “approaching the end of her growth” with “no treatment complications.”³³ The authors of the article concluded that the combination of treatments should be a “therapeutic option available” to other profoundly developmentally disabled children “should their parents request it.”³⁴

A. *Ashley’s Parents Go Public*

In January 2007, the parents of the child subject of Gunther and Diekema’s article set up a website³⁵ in order to respond to the media, “help families who might bring similar benefits to their bedridden Pillow Angels,” and “address some misconceptions about the treatment and [their] motives for undertaking it.”³⁶ Although the parents themselves chose to remain anonymous, they identified the patient described in the article as their daughter Ashley.³⁷ In an essay published on their Web site, Ashley’s parents revealed that the child underwent not only growth-impairing high-dose estrogen therapy and a hysterectomy, but also breast

30. *Id.*

31. *Id.* Carlson and Dorfman criticized Jones’ legal opinion as “not supported by a reasonable interpretation of pertinent law.” *Id.*

32. *Id.* The child’s surgeon later stated that he believed the letter setting forth Jones’ legal opinion “satisfied the requirement for ‘court review.’” *Id.*

33. Gunther & Diekema, *supra* note 3, at 1014.

34. *Id.* at 1013.

35. Ashley’s Parents, The “Ashley Treatment,” <http://ashleytreatment.spaces.live.com> (last visited Nov. 11, 2009); see also Frank Sennett, *Washington Couple Posts Blog Heard Round the World*, SPOKESMAN-REVIEW, Jan. 15, 2007, at 13A; Sam Howe Verhovek, *Stunting Disabled Girl’s Growth Triggers Ethical Firestorm—Parents Explain Decision on Web Site, Say Choice Made for Humane Reasons*, SOUTH FLA. SUN-SENTINEL, Jan. 28, 2007, at 1H.

36. Ashley’s Mom & Dad, The “Ashley Treatment”: Towards a Better Quality of Life for “Pillow Angels,” at 1 (Mar. 25, 2007), <http://pillowangel.org/Ashley%20Treatment%20v7.pdf> [hereinafter Ashley’s Mom & Dad, *Ashley Treatment Summary*]. Ashley’s parents use the term “pillow angel” to describe their daughter (and children with similar disabilities) because Ashley “is so sweet and stays right where [they] place her—usually on a pillow.” *Id.* Ashley’s parents assert that “pillow angels” is “a new category of disability,” and estimate that under one percent of all disabled children fit into this category. “*Pillow Angel! Parents Answer CNN’s Questions*, CNN.COM, Mar. 12, 2008, <http://www.cnn.com/2008/HEALTH/conditions/03/12/pillow.QA/index.html>. They further opine that although “society does not know much about [pillow angels] and their special needs,” it is “abundantly obvious that increased weight and height are the worst enemy for pillow angels.” *Id.* Many disability rights advocates take issue with the term “pillow angel,” viewing the characterization as an assault on the dignity of the disabled child. See, e.g., Gibbs, *supra* note 10, at 56 (quoting disability rights advocate Julia Epstein, speaking on behalf of the Disability Rights Education and Defense Fund, as saying “I know that’s meant to be a sweet term, but it’s terminally infantilizing”).

37. Ashley’s Mom & Dad, *Ashley Treatment Summary*, *supra* note 36.

bud removal.³⁸ Following the lead of Ashley’s parents, this “collection of procedures” has come to be known—and almost exclusively referred to in the media—as the “Ashley Treatment.”³⁹

Ashley’s parents have repeatedly asserted that the decision to have Ashley undergo the Ashley Treatment was “not a difficult one.”⁴⁰ The only “downside,” in their view, was the risk involved in the surgical procedures themselves.⁴¹ Ashley’s parents list numerous incidental benefits of the Ashley Treatment,⁴² but their three primary goals were (1) to limit Ashley’s final height in order to increase mobility and the likelihood that they would be able to continue to care for Ashley in the home, (2) to remove Ashley’s uterus in order to eliminate future menstrual discomfort, and (3) to remove Ashley’s breast buds⁴³ in order to eliminate the potential discomfort that would be caused if Ashley developed large breasts.⁴⁴

B. Widespread Response to the Ashley Treatment

The publication of Gunther and Diekema’s report, followed by Ashley’s parents going public with their daughter’s case, incited heated responses in opposition to the Ashley Treatment from the disability

38. *Id.* at 5. The treatment also included an appendectomy to “[e]liminate [the] possibility of [a]ppendicitis.” Ashley’s Parents, *Flowchart*, *supra* note 7.

39. Ashley’s Mom & Dad, *Ashley Treatment Summary*, *supra* note 36, at 4 (noting that the term “the Ashley Treatment” is “easy to remember and search for,” and the fact that—to their knowledge—“Ashley is the first child to receive this treatment”). Professor Ouellette argues that the term “treatment” in this case is a misnomer. Ouellette, *supra* note 13, at 210 n.7. “Treatment is ‘[a] broad term covering all the steps taken to effect a cure of an injury or disease . . .’” *Id.* (quoting BLACK’S LAW DICTIONARY 1346 (5th ed. 1979)). But “Ashley’s growth was not an injury or disease,” and the Ashley Treatment “did not effect a cure of any medical condition.” *Id.* Nonetheless, for the sake of clarity, the phrase “the Ashley Treatment” will be used throughout this Note to refer to the combination of high-dose estrogen therapy, hysterectomy, and breast bud removal.

40. Ashley’s Mom & Dad, *Ashley Treatment Summary*, *supra* note 36, at 4.

41. *See, e.g., id.* at 5.

42. *See* Ashley’s Parents, *Flowchart*, *supra* note 7 (listing secondary benefits to the Ashley Treatment, such as the elimination of the possibility of future breast or uterine cancer, elimination of the possibility of ovarian cysts, and avoidance of “sexualization towards caregiver”). As a side note, the argument that the Ashley Treatment is necessary because without it Ashley would be vulnerable to “sexualization” and possible sexual assault by her caregivers raises interesting issues that are beyond the scope of this Note, including the perceived sexual availability of women with mental disabilities, and—even more fundamentally—the highly gendered underpinnings of the Ashley Treatment and similar interventions. For an interesting and relevant discussion of the sexuality of disabled women in the context of sterilization, see Kristin Savell, *Sex and the Sacred: Sterilization and Bodily Integrity in English and Canadian Law*, 49 MCGILL L.J. 1093, 1129–34 (2004) (arguing that “the female body as it is constituted in law is a body for sex with men,” and that, unfortunately, “this attitude of resignation to the possibility of sexual assault obviate[s] the need to look to the quality of care [a disabled woman is] receiving to judge whether more could be done to protect her from the openly recognized risk of sexual assault”).

43. While Ashley’s “parents refer to this part of the interventions by the more benign sounding ‘breast bud removal,’” the Ethics Committee that reviewed the protocol used the term “mastectomy” to refer to this particular procedure. Ouellette, *supra* note 13, at 212 n.23. The terms “breast bud removal” and “mastectomy” are used interchangeably throughout this Note.

44. Ashley’s Parents, *Flowchart*, *supra* note 7.

rights community and others.⁴⁵ Many activists called for a legislative moratorium on medical growth-attenuation treatments for disabled children.⁴⁶ Some saw the Ashley Treatment as mutilation for the parents' convenience, and a tragic effort by the parents to permanently infantilize their disabled daughter.⁴⁷ The American Association on Intellectual and Developmental Disabilities declared that nonmedically necessary growth attenuation is a "totally unacceptable option" for children with disabilities.⁴⁸ Others, such as the National Council on Independent Living, denounced the use of medically unnecessary growth attenuation as a violation of the fundamental bodily integrity rights of those with disabilities.⁴⁹ Disability rights activists also attacked Ashley's parents' alleged motivations for the interventions,⁵⁰ arguing, for example, that "[t]his is an issue of basically subjecting a child to drastic physical alterations to fit the convenience of her caregivers."⁵¹ Still, others argued that the Ashley Treatment was "a dangerous precedent that could be used to justify additional invasive elective procedures on people with disabilities."⁵² For example, one critic highlighted the "enormous potential for abuse" by arguing that "restricted caloric intake to minimize weight or even 'amputation therapy'" could be next.⁵³

Nonetheless, some spoke out in support of the Ashley Treatment and similar growth-attenuation interventions as an option for parents of

45. For a thorough discussion of the disability rights groups and advocates reactions to the Ashley Treatment, see Ouellette, *supra* note 13, at 217–21. See also Shannon & Savage, *supra* note 11, at 177; Elizabeth Cohen, *Disability Community Decries "Ashley Treatment,"* CNN.COM, Jan. 12, 2007, <http://www.cnn.com/2007/HEALTH/01/11/ashley.outcry/index.html>.

46. Ouellette, *supra* note 13, at 219–20. Professor Ouellette explains that the "disability community's call for prohibition goes too far," arguing that prohibition is not only unwise policy, but not "necessary to protect children." *Id.* at 239–40. She argues that the "outright prohibition of a particular medical procedure is appropriate" only if the procedure is one that would *never* be justified; in other words, absolute prohibition should only be pursued when the "subject intervention is unacceptable for everyone." *Id.* at 240. For example, the federal government has banned female genital mutilation because of its decision that "the procedure is never medically appropriate," regardless of whether the patient is disabled or not. *Id.* An outright "ban on the use of hysterectomy, mastectomy, or hormone treatment in the developmentally disabled" would be legally problematic, however, because "these procedures are available for people without disabilities," even for purely social reasons. *Id.* at 241. Thus, a prohibition would raise equal protection and discrimination concerns: "Banning their use in people with disabilities might be as discriminatory as forcing them on people with disabilities." *Id.* This reflects Norman Cantor's argument that "profoundly disabled persons ought to be accorded access to a full range of potentially beneficial medical interventions." CANTOR, *supra* note 14, at 69.

47. Carole L. Marcus, Response, *Only Half the Story*, 161 ARCHIVES PEDIATRICS & ADOLESCENT MED. 616, 616 (2007).

48. Am. Ass'n on Intellectual & Developmental Disabilities, Board Position Statement: Growth Attenuation Issue, http://www.aamr.org/content_173.cfm?navID=31 (last visited Nov. 11, 2009).

49. Nat'l Council on Indep. Living, *supra* note 15.

50. See Ouellette, *supra* note 13, at 218.

51. Dave Reynolds, *Advocates Speak Out and Call for Investigations over "Ashley Treatment,"* INCLUSION DAILY EXPRESS, Jan. 12, 2007, <http://www.inclusiondaily.com/archives/07/01/12/011207waashleyx.htm> (quoting Stephen Drake, speaking on behalf of Not Dead Yet, a disability rights organization).

52. Ouellette, *supra* note 13, at 219.

53. Hank Bersani, *Growth Attenuation: Unjustifiable Non-therapy*, 161 ARCHIVES PEDIATRICS & ADOLESCENT MED. 520, 521 (2007) (speaking on behalf of the American Association on Mental Retardation, now known as the American Association on Intellectual and Developmental Disabilities).

profoundly developmentally disabled children.⁵⁴ One observer reasoned that Ashley and other profoundly developmentally disabled children “lack[] the cognitive capacity to experience any sense of indignity,” and that the Ashley Treatment will endow such a child “with a body that more closely matches her [or his] cognitive state.”⁵⁵ In other words, “[t]he estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.”⁵⁶ Others have cited economic justifications, arguing that, while it would be preferable to “change the home to fit Ashley” instead of “chang[ing] Ashley to fit the home,” that “utopian view of care” is not made possible by the meager level of public funding available for families of disabled children.⁵⁷ Thus, the argument goes, by “allowing parents of severely developmentally disabled children to have access to growth attenuation treatment,” they are not abandoned to the “harsh social and economic realities” experienced by those struggling to care for these children.⁵⁸

C. *The WPAS Investigation and Report*

In the midst of the unfolding public controversy over the Ashley Treatment,⁵⁹ the Washington Protection and Advocacy System (WPAS), a federally mandated agency that provides “protection and advocacy services to individuals with disabilities in the state of Washington” acting under its “specific authority to investigate incidents of alleged abuse and neglect,” initiated an investigation into the case of Ashley X.⁶⁰ The investigative report concluded that, under Washington state law, a court order is necessary “when parents seek to sterilize their minor . . . children.”⁶¹ Thus, because Ashley’s parents and physicians failed to obtain a court order authorizing Ashley’s sterilization, the sterilization procedure violated Washington common law and Ashley’s “constitutional and common law rights.”⁶² In addition, the report found that “[c]ourts have also limited parental authority to consent to other types of medical interventions that are highly invasive and/or irreversible, particularly

54. See, e.g., Shannon & Savage, *supra* note 11, at 175.

55. Posting of George Dvorsky to Sentient Developments, Helping Families Care for the Helpless, http://www.sentientdevelopments.com/2006/11/helping-families-care-for-helpless_06.html (Nov. 6, 2006).

56. *Id.*; see also John W. Dienhart & Paul Glezen, *On Ethics: Ashley's Treatment: Whose Business? Which Ethics?*, SEATTLE POST-INTELLIGENCER, Jan. 14, 2007, at D6 (“Perhaps the Ashley procedure brings Ashley’s entire self into harmony.”).

57. Shannon & Savage, *supra* note 11, at 177.

58. *Id.*

59. See Ouellette, *supra* note 13, at 220.

60. See CARLSON & DORFMAN, *supra* note 2, at 5, 8 (citations omitted). Although WPAS changed its name to Disability Rights Washington on June 1, 2007, I will refer to the organization as WPAS throughout this Note. Washington Protection & Advocacy System, <http://www.wpas-rights.org/> (last visited Nov. 11, 2009).

61. CARLSON & DORFMAN, *supra* note 2, at 1.

62. *Id.*

when the interest of the parent may not be identical to the interest of the child.”⁶³ Thus, WPAS concluded that mastectomy and growth-attenuating hormone treatments “should . . . require independent court evaluation and sanction before being performed on any person with a developmental disability.”⁶⁴ Finally, the report concluded that the Ashley Treatment raised issues of discrimination in violation of state and federal law because “if not for the individual’s developmental disabilities, the interventions would not be sought.”⁶⁵ Interestingly, although the report strongly criticized the hospital’s procedures surrounding the case of Ashley X, WPAS did not issue an opinion on whether a reviewing court would have approved the procedures in Ashley’s case, nor did it opine as to whether any court should approve similar interventions in the future.⁶⁶

As outlined in the report, WPAS reached a settlement with the hospital where the Ashley Treatment was performed, under which the hospital agreed to implement a policy prohibiting both sterilization and medical growth attenuation of developmentally disabled persons in the absence of a court order.⁶⁷ The hospital also consented to notify WPAS whenever sterilization or growth-attenuation procedures are requested on behalf of disabled individuals, in order for WPAS to “continue to act as a watchdog on behalf of individuals with disabilities.”⁶⁸ In addition, the hospital agreed to include a disability rights advocate on their internal ethics committee.⁶⁹ WPAS further promised to reach out to other hospitals to encourage them to adopt similar policies for protecting patients with developmental disabilities.⁷⁰

D. The Aftermath: Nontherapeutic Growth Attenuation as an Option for Parents of Severely Developmentally Disabled Children

Despite the intense opposition to the Ashley Treatment by the disability rights community and the negative findings of the WPAS report, some people—most notably parents of disabled children—have expressed support for, and interest in, the Ashley Treatment as a medical option for their own children.⁷¹ Parents of disabled children around the country have begun to approach physicians seeking this type of growth-

63. *Id.*

64. *Id.*

65. *Id.*

66. See Ryan, *supra* note 17, at 293.

67. See CARLSON & DORFMAN, *supra* note 2, at 2.

68. *Id.*

69. *Id.*

70. *Id.* at 3.

71. See Ed Pilkington, *Parents of Disabled Children Ask Doctors for “Ashley Treatment,”* GUARDIAN (LONDON), Jan. 8, 2007, at 20; see also Testimonies from Other Families, Ashley’s Blog, <http://ashleytreatment.spaces.live.com/blog/cns!E25811FD0AF7C45C!1826.entry> (Dec. 6, 2007, 03:56 EST).

attenuating intervention for their own children.⁷² Furthermore, Dr. Diekema himself has noted that some have criticized his two primary suggested criteria for determining whether children should qualify for growth-attenuating interventions—that they be (1) profoundly and permanently cognitively disabled, and (2) permanently nonambulatory—as too strict,⁷³ suggesting that the Ashley Treatment and similar procedures should also be available for less profoundly disabled children.⁷⁴ In light of the potential for the Ashley Treatment to be administered on countless disabled children,⁷⁵ it is critical to examine whether this unique category of medical intervention violates the profoundly developmentally disabled child’s rights—in particular, the fundamental right to bodily integrity—and, if so, determine what legal steps can be taken to protect these children’s rights when parents request the Ashley Treatment and similar growth-attenuating interventions.

III. ANALYSIS OF THE FUNDAMENTAL RIGHT TO BODILY INTEGRITY

The right to bodily integrity, which “safeguards the physical parameters of a person,” has been called “the cornerstone of all other liberties.”⁷⁶ Bodily integrity is a foundational principle underlying the common law, statutes, and constitutional law.⁷⁷ The substantive due process guarantee of the Fourteenth Amendment provides, in part, that “[n]o state shall . . . deprive any person of life, liberty, or property, without due process of law.”⁷⁸ The liberty protected by the Fourteenth Amendment “protects more than the absence of physical restraint”—rather, it “provides heightened protection against government interference with certain fundamental rights.”⁷⁹ Fundamental rights are those that are “so rooted in the traditions and conscience of our people as to be ranked as fundamental” or are “implicit in the concept of ordered liberty.”⁸⁰ The Su-

72. See, e.g., Rebecca Clarren, *Behind the Pillow Angel*, SALON.COM, Feb. 9, 2007, http://www.salon.com/news/feature/2007/02/09/pillow_angel/index.html.

73. Douglas Diekema, Remarks at the University of Washington Disability Studies Program and Seattle Children’s Hospital Treuman Katz Center for Pediatric Bioethics Symposium: The Ethical and Policy Implications of Limiting Growth in Children with Severe Disabilities (May 16, 2007), available at <http://www.seattlechildrens.org/research/initiatives/bioethics/events/limiting-growth-children-disabilities/> (select “Philosophical Perspectives About Growth Attenuation: Discussion and Questions with the Panelists” hyperlink).

74. Detailed Report on “Ashley Treatment” (Growth Attenuation, Etc.) Symposium at University of Washington, eminism.org, <http://eminism.org/blog/entry/16> (May 17, 2007).

75. Randy Dotinga, *The Mysteries of Mental Age*, WIRED, Feb. 7, 2007, <http://www.wired.com/medtech/health/news/2007/02/72569>.

76. Christyne L. Neff, *Woman, Womb, and Bodily Integrity*, 3 YALE J.L. & FEMINISM 327, 328 (1991).

77. HOWARD BALL, *THE SUPREME COURT IN THE INTIMATE LIVES OF AMERICANS* 18 (2002); Eileen L. McDonagh, *My Body, My Consent: Securing the Constitutional Right to Abortion Funding*, 62 ALB. L. REV. 1057, 1061 (1999).

78. U.S. CONST. amend. XIV, § 1.

79. *Washington v. Glucksberg*, 521 U.S. 702, 719–20 (1997).

80. *Rochin v. California*, 342 U.S. 165, 169 (1952) (citations omitted).

preme Court has held that, “in addition to the specific freedoms protected by the Bill of Rights, the ‘liberty’ specially protected by the Due Process Clause includes the right[] . . . to bodily integrity.”⁸¹

A. *“The Right to Be Let Alone”: The History of the Right to Bodily Integrity*

The right to bodily integrity is “one of the oldest fundamental rights recognized by the law,”⁸² and is a “fundamental tenet[] of a democratic society, long established in the history and legal foundations” of our country.⁸³ William Blackstone’s theory of bodily integrity is often cited as the origin of the common law right.⁸⁴ Blackstone viewed the human body as “sacred” and argued that no person has the right “to meddle with” another person’s body.⁸⁵ While the term “sacred” gradually faded out of the language of bodily integrity jurisprudence, modern articulations of the right to bodily integrity have preserved the essence of Blackstone’s formulation by characterizing bodily integrity as “inviolable,” or “not to be violated.”⁸⁶ In other words, the right to bodily integrity “safeguards the physical parameters of a person.”⁸⁷

In *Union Pacific Railway Co. v. Botsford*, the Supreme Court stated that “[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”⁸⁸ The Court further described this “deeply rooted” right to bodily integrity⁸⁹ as “a right of complete immunity; *to be let alone*.”⁹⁰ This articulation of the right to bodily integrity has led scholars to the understanding that “[u]ltimately, despite the context, bodily integrity is the ‘centuries-old right to be left alone.’”⁹¹ The Court itself has continued to affirm this statement of the right, for instance, through its repeated reference to Justice Brandeis’ statement in *Olmstead v. United States*⁹² that “[the makers of our Constitution] conferred, as against the Government, the right *to*

81. *Glucksberg*, 521 U.S. at 720. The right to bodily integrity is arguably also protected by the First, Fourth, Fifth, and Eighth Amendments, and the common law. See B. Jessie Hill, *The Constitutional Right to Make Medical Treatment Decisions: A Tale of Two Doctrines*, 86 TEX. L. REV. 277, 304–05 (2007); Neff, *supra* note 76, at 337.

82. Hill, *supra* note 81, at 304.

83. DAVID W. MEYERS, *THE HUMAN BODY AND THE LAW* 155 (2d ed. Stanford Univ. Press 1990) (footnote omitted).

84. Savell, *supra* note 42, at 1105.

85. *Id.*

86. *Id.*

87. Neff, *supra* note 76, at 328.

88. *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891).

89. MEYERS, *supra* note 83, at 38.

90. *Botsford*, 141 U.S. at 251 (emphasis added) (citation omitted).

91. Stephanie Weiler, Comment, *Bodily Integrity: A Substantive Due Process Right to Be Free from Rape by Public Officials*, 34 CAL. W. L. REV. 591, 595 (1998) (citation omitted).

92. 277 U.S. 438 (1928).

be let alone—the most comprehensive of rights and the right most valued by civilized men.”⁹³

Lower courts also began to acknowledge and uphold the right to bodily integrity during this time. In *Pratt v. Davis*, the Illinois Appellate Court asserted that

under a free government at least, the free citizen’s *first and greatest right*, which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician or surgeon . . . to violate without permission the bodily integrity of his patient⁹⁴

While serving on the New York Court of Appeals, Justice Cardozo provided another enduring formulation of the right to bodily integrity when he famously wrote that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.”⁹⁵ Cardozo’s early statement of the right to bodily integrity is still invoked by the Court when describing the right to bodily integrity in the context of medical decision making.⁹⁶

B. *The Modern Constitutional Status of the Right to Bodily Integrity*

Since the late nineteenth century, the Supreme Court has recognized the right to bodily integrity as a fundamental right requiring heightened constitutional protection.⁹⁷ In *Rochin v. California*,⁹⁸ the Court recognized that “a person’s constitutional right to liberty protected by the Due Process Clause includes the right to bodily integrity.”⁹⁹ At issue was the fact that the defendant was convicted on the basis of evidence that law enforcement officers had obtained by forcibly pumping the defendant’s stomach and inducing vomiting against the defendant’s will.¹⁰⁰ The Court, declaring that the law enforcement officers’ conduct “shocks the conscience,” held that the defendant’s due process rights were vi-

93. *Id.* at 478 (Brandeis, J., dissenting) (emphasis added); *see also* *Washington v. Harper*, 494 U.S. 210, 238 (1990) (invoking Justice Brandeis’ quote from *Olmstead* to describe the fundamental right to bodily integrity).

94. *Pratt v. Davis*, 118 Ill. App. 161, 166 (App. Ct. 1905), *aff’d*, 79 N.E. 562 (Ill. 1906).

95. *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

96. *See, e.g., Washington v. Glucksberg*, 521 U.S. 702, 777 (1997) (Souter, J., concurring in the judgment) (using then-Judge Cardozo’s above quotation to describe the “liberty interest in bodily integrity . . . in a general way”).

97. *See Weiler, supra* note 91, at 597; *see also* J. Steven Svoboda et al., *Informed Consent for Neonatal Circumcision: An Ethical and Legal Conundrum*, 17 J. CONTEMP. HEALTH L. & POL’Y 61, 63 (2000) (“In this century, courts have increasingly emphasized the strong interest each person has in being free from nonconsensual invasion of his bodily integrity.”). “As early as 1891, the Supreme Court had refused to permit a forced medical examination of a litigant . . . reasoning that it would violate the deeply rooted right of bodily integrity and ‘to be let alone.’” MEYERS, *supra* note 83, at 38.

98. 342 U.S. 165 (1952).

99. McDonagh, *supra* note 77, at 1061; *see also* BALL, *supra* note 77, at 18.

100. *See Rochin*, 342 U.S. at 166.

olated by the officers “[i]llegally breaking into” the defendant’s body.¹⁰¹ Although the Court did not use the phrase “bodily integrity” to describe the substantive due process violation in that case,¹⁰² the Court has subsequently cited *Rochin* as an example of its upholding the fundamental right to bodily integrity.¹⁰³

Since *Rochin*, the Supreme Court “has repeatedly held that there is a right to be free from unjustified intrusions on personal bodily integrity.”¹⁰⁴ Among other things, the Court has held that the right to bodily integrity entitles families to make birth control decisions,¹⁰⁵ women to have abortions,¹⁰⁶ and individuals to make end of life decisions,¹⁰⁷ free from government and control.¹⁰⁸ Particularly of note in the context of medical decision making are *Cruzan v. Director, Missouri Department of Health*¹⁰⁹ and *Washington v. Glucksberg*,¹¹⁰ in which the Court emphasized the competent person’s “right to reject even life-sustaining medical intervention.”¹¹¹ This so-called “right to die” is based on the fundamental right to bodily integrity and the Supreme Court’s “accompanying revulsion toward the spectacle of forcing an unwilling person to receive treatment.”¹¹²

Following the lead of the Supreme Court, modern lower courts have “consistently respected the principle of bodily integrity and zealously promoted it as sacred, inviolable, inalienable, and fundamental.”¹¹³ Courts have consistently upheld this right to bodily integrity in a variety of contexts, including “unsolicited medical procedures, forcible stomach pumping, corporal punishment in schools, the decision to forego medical treatment, decisions regarding birth control, and abortion.”¹¹⁴

Although the Court has stated that “[e]very violation of a person’s bodily integrity is an invasion of his or her liberty,”¹¹⁵ the right to bodily integrity is not absolute.¹¹⁶ “The same constitutional jurisprudence that recognizes an important interest in bodily integrity also recognizes that

101. *Id.* at 172, 174.

102. See Rosalie Berger Levinson, *Reining In Abuses of Executive Power Through Substantive Due Process*, 60 FLA. L. REV. 519, 542 (2008).

103. See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997); *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 849 (1992).

104. Weiler, *supra* note 91, at 596.

105. See *Griswold v. Connecticut*, 381 U.S. 479, 485 (1965).

106. See *Casey*, 505 U.S. at 896–98.

107. See *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 277–78 (1990); see also *Glucksberg*, 521 U.S. at 722–23 (explaining *Cruzan*’s holding as a “constitutionally protected right to refuse lifesaving hydration and nutrition” while upholding Washington’s statutory ban on physician-assisted suicide).

108. Weiler, *supra* note 91, at 594.

109. *Cruzan*, 497 U.S. 261.

110. *Glucksberg*, 521 U.S. 702.

111. CANTOR, *supra* note 14, at 120.

112. *Id.*

113. Neff, *supra* note 76, at 337.

114. Weiler, *supra* note 91, at 596–97 (footnotes omitted).

115. *Washington v. Harper*, 494 U.S. 210, 237 (1990) (Stevens, J., concurring in part and dissenting in part).

116. See CANTOR, *supra* note 14, at 120.

various competing interests can sometimes prevail”¹¹⁷ Thus, in any situation that involves a bodily invasion, the severity of the invasion of the individual’s fundamental right to bodily integrity must be “balanced against state interests such as public health, safety and welfare, the integrity of the medical profession, criminal investigation, and the preservation of life.”¹¹⁸ For example, state interests such as “public health can justify compulsory vaccination, public safety can warrant blood alcohol tests, and well-founded needs of law enforcement can sometimes justify searches of bodily cavities or even surgical intrusions.”¹¹⁹ Nonetheless, “courts have held in the majority of cases that bodily integrity is the prevailing interest.”¹²⁰

C. The Fundamental Right to Bodily Integrity As Applied to Severely Developmentally Disabled Children

Although some philosophers would disagree,¹²¹ American law recognizes “all live human beings as rights-bearing persons with full moral stature,” including the profoundly developmentally disabled.¹²² This constitutional protection attaches to every American citizen at live birth¹²³ and is retained regardless of the individual’s level of intellectual functioning.¹²⁴ Courts generally strive to uphold the principle that “a profoundly disabled human is no ‘less worthy of dignity and respect in the eyes of the law than a competent person.’”¹²⁵ Many courts, for example, have stated that “disabled persons enjoy ‘the same panoply of rights and choices’ as fully capacitated persons.”¹²⁶

In practice, however, this broad theory of rights is less straightforward in the context of medical decision making and the profoundly deve-

117. *Id.*

118. Neff, *supra* note 76, at 337–38.

119. CANTOR, *supra* note 14, at 120.

120. Neff, *supra* note 76, at 338.

121. There are two overarching views on the concept of personhood. CANTOR, *supra* note 14, at 20. Some philosophers argue that personhood is “grounded in intellectual function”; that is, “personhood requires a level of intellectual function that would exclude some or all profoundly disabled beings.” *Id.* at 17, 20. Other philosophers, however, argue that personhood is grounded in “species membership,” arguing that “all human beings, regardless of intellectual function, have full moral status.” *Id.* at 19–20. This latter view is reflected in American constitutional law. *Id.* at 20.

122. *Id.* at 20 (emphasis added); see also William A. Kraus, Note, *The Incompetent Developmentally Disabled Person’s Right of Self-Determination: Right-to-Die, Sterilization, and Institutionalization*, 15 AM. J.L. & MED. 333, 333 (1989).

123. CANTOR, *supra* note 14, at 20; see *Roe v. Wade*, 410 U.S. 113, 158–60 (1973).

124. CANTOR, *supra* note 14, at 20–21. Even in cases of permanently unconscious persons with no perceived level of intellectual functioning, the Supreme Court has not “hesitated in accepting permanently unconscious patients as persons deserving of . . . constitutional protection.” *Id.* at 22.

125. *Id.* at 21 (quoting *In re Hocker*, 791 N.E.2d 302, 307 (Mass. 2003)).

126. *Id.* at 35 (quoting Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 428 (Mass. 1977) (“To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons.”)); see also, e.g., *Myers v. Alaska Psychiatric Inst.*, 138 P.3d 238, 247 n.59 (Alaska 2006); *In re Zaltman*, 843 N.E.2d 663, 673 n.20 (Mass. App. Ct. 2006).

lopmentally disabled child.¹²⁷ Because the profoundly developmentally disabled child is unable to make autonomous choices, and the “right to refuse medical intervention is, in part, grounded in self-determination—a weighing and choosing among competing options”—the profoundly developmentally disabled child cannot exercise “the *same* right” to refuse medical intervention as the competent person.¹²⁸ Thus, “finding a practical framework that allows others to make decisions and yet assures the correctness of those decisions for that patient presents a legal and ethical challenge.”¹²⁹

Nonetheless, just because these children “cannot enjoy ‘the same right’ as the decisionally capacitated does not mean that they have . . . no liberty-based constitutional rights.”¹³⁰ Specifically, even though they cannot personally exercise their right to bodily integrity,¹³¹ developmentally disabled children fully retain that right—“that is, freedom from unnecessary bodily invasion.”¹³² Thus, when it comes to medical decision making, profoundly developmentally disabled children have “important potential interests” at stake—their fundamental right to bodily integrity—even though self-determination is not possible.¹³³

In the context of the Ashley Treatment and similar nonmedically necessary growth-attenuation interventions, the above description of the incompetent child’s right to bodily integrity begs the question: how can the profoundly developmentally disabled child’s fully present and fundamental right to bodily integrity be preserved in the absence of an ability to consent to highly invasive, irreversible, and unnecessary medical interventions?¹³⁴ Because severely developmentally disabled children cannot exercise these rights themselves, it falls on others—usually parent or guardians, and sometimes the state—to ensure that the child’s right are acknowledged and protected.¹³⁵ The following Part discusses the process of medical decision making on behalf of profoundly developmentally disabled children, and ultimately argues that—under the doctrine of *parens patriae*—a court has an affirmative duty to step in as a surrogate decision maker when a parent desires a profoundly developmentally dis-

127. See CANTOR, *supra* note 14, at 36 (“The notion that profoundly disabled persons have the *same* right to choose as the abled is inaccurate.”).

128. *Id.* at 36–37 (emphasis added); see also Kraiss, *supra* note 122, at 333.

129. Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*, 7 MICH. J. GENDER & L. 1, 37 (2000).

130. See CANTOR, *supra* note 14, at 37.

131. See MEYERS, *supra* note 83, at 155 (noting that a patient who is unable to give consent due to age or incompetence “is not personally able to exercise” the right to bodily integrity).

132. See CANTOR, *supra* note 14, at 37–38; see also MEYERS, *supra* note 83, at 30 (stressing that “the bodily integrity of the incompetent [is] just as important as [that] of the competent”).

133. See CANTOR, *supra* note 14, at 38.

134. See *id.* at 69 (noting that, if the profoundly disabled person’s right to access “a full range of potentially beneficial medical interventions” is to be fulfilled, “someone (a surrogate) must decide on behalf of the incapacitated patient whether to institute any medical intervention in issue”).

135. See Kraiss, *supra* note 122, at 334.

abled child to undergo nontherapeutic medical interventions that pose a significant potential for a parental conflict of interest and threaten to impair the child's fundamental rights, particularly the right to bodily integrity.

IV. ANALYSIS OF MEDICAL DECISION MAKING FOR PROFOUNDLY DEVELOPMENTALLY DISABLED CHILDREN: PARENTAL DISCRETION VERSUS JUDICIAL INTERVENTION

Children are generally considered legally incompetent to consent to their own medical treatment.¹³⁶ This is largely premised on two underlying assumptions: that children are unable to fully understand the nature and consequences of a proposed medical course of action,¹³⁷ and that they do not possess the level of maturity necessary to ensure that they will make decisions that are in their own best interests.¹³⁸ Instead, the law typically entrusts parents with the “right and responsibility” to consent to medical procedures on behalf of their children.¹³⁹ “As long as these decisions are in line with an accepted medical standard of care, courts will rarely intervene in them.”¹⁴⁰ Courts and legislatures, however, have recognized that certain types of medical decisions—specifically, those involving nontherapeutic procedures that pose significant potential for conflict of interest between the parents and child and threaten to substantially impair the child's fundamental rights—are not suited for the typical model of parental decision making.¹⁴¹ Thus, certain “categorical exceptions” to the general parental authority presumption have developed, in which entire categories of medical decisions are removed from the exclusive control of parents and subjected to judicial oversight under the doctrine of *parens patriae*.¹⁴²

A. Parental Authority to Consent to Medical Treatment

The general presumption of parental authority to make medical decisions on behalf of children primarily stems from two sources: the legal presumption that parents generally make decisions that are in the best interests of their child, and the constitutional right of parental discre-

136. Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. GENDER L. & JUST. 59, 79 (2006).

137. See Sara R. Benson, *Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed*, 12 CARDOZO J.L. & GENDER 31, 36 (2005).

138. Ross Povenmire, *Do Parents Have the Legal Authority to Consent to the Surgical Amputation of Normal, Healthy Tissue from Their Infant Children?: The Practice of Circumcision in the United States*, 7 AM. U. J. GENDER SOC. POL'Y & L. 87, 101 (1999).

139. MEYERS, *supra* note 83, at 155, 164; Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 5 (2000).

140. Tamar-Mattis, *supra* note 136, at 79.

141. *Id.* at 93, 96.

142. *Id.* at 93.

tion.¹⁴³ First, the law generally presumes that parents act benevolently toward their children.¹⁴⁴ This presumption is based on the historically recognized principle that “natural bonds of affection lead parents to act in the best interests of their children.”¹⁴⁵ It is also premised on the notion that “parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions.”¹⁴⁶ The law assumes that parents will weigh all of a child’s interests, such as the “interests of the child in bodily integrity” and “avoidance of unnecessary surgery,” when making a medical decision on behalf of that child.¹⁴⁷ “[S]o long as a parent adequately cares for his or her children . . . there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent’s children.”¹⁴⁸

Second, the Supreme Court has interpreted the Due Process Clause of the Fourteenth Amendment to generally shield parental decision making from state interference.¹⁴⁹ In a line of cases beginning with *Meyer v. Nebraska*,¹⁵⁰ the Court protected the right of parents to “direct the upbringing” of their children against state interference,¹⁵¹ especially in areas such as education and religion.¹⁵² For example, the Court has found that parents have the right to expose their children to foreign-language education,¹⁵³ to send their children to private schools,¹⁵⁴ and to remove their children from high school prior to graduation for religious reasons.¹⁵⁵ Furthermore, the Court has repeatedly suggested that this right to parental discretion in child-rearing is fundamental in nature,¹⁵⁶ although it has yet to clearly define the nature and scope of this right.¹⁵⁷

143. *Id.* at 79. Meyers suggests a third rationale for the general presumption of parental authority to consent: practicality. MEYERS, *supra* note 83, at 164 (arguing that the parental authority presumption also partially “derives from the impracticality of trying to regulate the parent-child relationship, particularly given the many divergent philosophies of child-rearing, religious viewpoints and social-cultural orientation among a polyglot population”).

144. CANTOR, *supra* note 14, at 128; *see Parham v. J. R.*, 442 U.S. 584, 604 (1979) (acknowledging the “traditional presumption that the parents act in the best interests of their child”).

145. *Parham*, 442 U.S. at 602.

146. *Id.*

147. Tamar-Mattis, *supra* note 136, at 90.

148. *Troxel v. Granville*, 530 U.S. 57, 68–69 (2000).

149. CANTOR, *supra* note 14, at 129; *see also Povenmire*, *supra* note 138, at 103; Rosato, *supra* note 139, at 5–6.

150. 262 U.S. 390, 399 (1923) (holding that the “liberty” guaranteed by the Fourteenth Amendment includes “the right . . . to marry, to establish a home and bring up children”).

151. *Wisconsin v. Yoder*, 406 U.S. 205, 232–33 (1972) (quoting *Pierce v. Soc’y of Sisters*, 268 U.S. 510, 534 (1925)).

152. CANTOR, *supra* note 14, at 128–29; Povenmire, *supra* note 138, at 103.

153. *Meyer*, 262 U.S. at 403.

154. *Pierce*, 268 U.S. at 535.

155. *Yoder*, 406 U.S. at 234. For a thorough discussion of the *Meyer* line of cases, including *Pierce* and *Yoder*, *see BALL*, *supra* note 77, at 127–39.

156. BALL, *supra* note 77, at 166; CANTOR, *supra* note 14, at 129; *see also, e.g., Griswold v. Connecticut*, 381 U.S. 479, 495 (1965) (Goldberg, J., concurring) (“The entire fabric of the Constitution and the purposes that clearly underlie its specific guarantees demonstrate that the rights to marital

B. Judicial Review of Parental Medical Decision Making

Parents generally retain broad discretion to make decisions on behalf of their children, but these rights are not absolute.¹⁵⁸ Parental authority is “not a right to do as the parent wishes with the child’s body,” or to make decisions “that are physically harmful to the child.”¹⁵⁹ Although it is generally true that parents act in their children’s best interests, the reality that parents occasionally act against the best interests of their children “may rebut what the law accepts as a starting point.”¹⁶⁰ Within the context of medical decision making, parental authority to decide “is circumscribed by the welfare of their children; they may not make decisions for their children that are likely to cause them physical harm or otherwise impair their healthy development.”¹⁶¹ In other words, the broad medical decision-making discretion possessed by parents is limited by the legal and ethical requirement that their decisions be in the best interests of the child.¹⁶² When parental decision making falls short of this threshold, state action is triggered.¹⁶³

The Supreme Court has affirmed this principle by readily curtailing parental discretion where a parental decision has threatened to negatively affect a child’s well-being.¹⁶⁴ In *Parham v. J. R.*, for example, the Court held, in regard to the admission of children to mental health facilities, that “the risk of error inherent in the parental decision to have a child institutionalized for mental health care is sufficiently great that some kind of inquiry should be made by a ‘neutral factfinder’ to determine whether the statutory requirements for admission are satisfied.”¹⁶⁵ While acknowledging the presumption of “broad parental authority over minor children,” the majority nonetheless emphasized that a state has “consti-

privacy and to marry and raise a family are of similar order and magnitude as the fundamental rights specifically protected.”).

157. Povenmire, *supra* note 138, at 103–04. Povenmire argues that, “[i]nstead of recognizing a broad constitutional right of parental discretion, [*Meyer, Pierce, and Yoder*] stand for a limited scope of parental discretion in areas of education and religion.” *Id.* at 103.

158. See BALL, *supra* note 77, at 166; MEYERS, *supra* note 83, at 164; Tamar-Mattis, *supra* note 136, at 79–80. Some scholars have argued that the strength of the presumption of parental decision making on behalf of their children is waning. See, e.g., Svoboda et al., *supra* note 97, at 86. “Recognition of and respect for children as persons distinct from their parents has grown, leading scholars and judges to insist that parenthood is a fiduciary role rather than a property-owning one, so that parental authority should be viewed as a limited privilege rather than as a right.” *Id.*

159. Tamar-Mattis, *supra* note 136, at 101.

160. *Parham v. J. R.*, 442 U.S. 584, 602 (1979).

161. Svoboda et al., *supra* note 97, at 83; see also MEYERS, *supra* note 83, at 155 (“[L]imitations have been imposed on the parents’ freedom of action in an effort to protect the welfare and best interest of the child.”).

162. Svoboda et al., *supra* note 97, at 84.

163. *Id.*

164. See Povenmire, *supra* note 138, at 103–04.

165. *Parham*, 442 U.S. at 606.

tutional control over parental discretion in dealing with children when their physical or mental health is jeopardized.”¹⁶⁶

1. *The Doctrine of Parens Patriae*

This inherent judicial authority to intervene in decisions affecting children stems from the equitable doctrine of *parens patriae*, which empowers courts to make decisions that are in the best interests of vulnerable persons.¹⁶⁷ “The state, in its role as *parens patriae*, or substitute parent, has an obligation, imposed by the common law, to see that actions effecting children and other incompetents are consistent with their welfare and best interests.”¹⁶⁸ *Parens patriae* confers on the state a “right, indeed, a duty, to protect children” by intervening “in family matters to safeguard the child’s health.”¹⁶⁹ This obligation to protect helpless individuals from abuse is an essential and traditional element of the relationship between citizens and the state.¹⁷⁰

In the context of medical decision making on behalf of minors, the state—through its courts—may exercise its power of *parens patriae* to override parental decisions.¹⁷¹ The court’s *parens patriae* power is particularly strong in this context because “the court is safeguarding both the interests of the state in ensuring the health of minors, as well as the right of minors in preserving bodily integrity.”¹⁷² Although the parental authority model generally governs medical decision making on behalf of children, there are situations where “the parents’ interest in being the decision-maker” might be outweighed by the “child’s interests in liberty, privacy, and bodily integrity.”¹⁷³ When parents request a procedure that “exposes their child to the clear risk of serious harm, the state and the courts will not hesitate to intervene to protect the welfare of the child.”¹⁷⁴ The risk to the child is especially great—and thus the need for *parens patriae* intervention especially acute—where the parent chooses “an extreme and medically unnecessary procedure, with uncertain outcome and

166. *Id.* at 602–03; *see also* Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (stating that “neither rights of religion nor rights of parenthood are beyond limitation,” and that in order to “guard the general interest in youth’s well being, the state as *parens patriae* may restrict the parent’s control by requiring school attendance, regulating or prohibiting the child’s labor, and in many other ways” (footnotes omitted)).

167. *See* SARAH F. HAAVIK & KARL A. MENNINGER, II, SEXUALITY, LAW, AND THE DEVELOPMENTALLY DISABLED PERSON 140 (1981); Povenmire, *supra* note 138, at 106–07; *see also* Troxel v. Granville, 530 U.S. 57, 88 (2000) (Stevens, J., dissenting) (“A parent’s rights with respect to her child have thus never been regarded as absolute [A] parent’s interests in a child must be balanced against the State’s long-recognized interests as *parens patriae* . . .”).

168. MEYERS, *supra* note 83, at 164.

169. *In re Phillip B.*, 156 Cal. Rptr. 48, 51 (Cal. Ct. App. 1979).

170. CANTOR, *supra* note 14, at 57.

171. Povenmire, *supra* note 138, at 106.

172. *Id.* at 107.

173. Tamar-Mattis, *supra* note 136, at 93.

174. MEYERS, *supra* note 83, at 164.

conflicts of interest for the caregivers.”¹⁷⁵ Ultimately, American judges possess “substantial discretion to decide what they think is best for the child where his or her health is at risk.”¹⁷⁶

2. *Categorical Exceptions to the Presumption of Parental Medical Decision-Making Authority*

Given the enormous risks inherent in certain categories of medical procedures requested by parents on behalf of children, courts and legislatures have developed “categorical exceptions” to the general presumption of parental medical decision-making authority.¹⁷⁷ If a parent seeks to obtain a procedure falling into one of these categories, the law generally provides for judicial review of parental decision making in order to safeguard the child’s rights.¹⁷⁸ In other words, “parental control is displaced in these areas . . . and the critical medical decision is assigned to the courts.”¹⁷⁹ Two of the best-developed and most widely recognized categorical exceptions to the parental authority model of medical decision making are child organ donation and child sterilization.¹⁸⁰

a. Existing Categorical Exceptions

When parents seek to have children serve as organ donors, courts routinely intervene in the decision-making process.¹⁸¹ The problem of parental choice became readily apparent in the context of organ donation, as observers expressed concerns that “helpless individuals would be exploited—without appropriate attention to their own interests—under the impetus of saving the lives of siblings or others.”¹⁸² This fear was especially acute where the potential child-donor was cognitively disabled, as it seemed likely that parents might “be terribly conflicted at the prospect of harvesting an organ from one child, especially an intellectually limited child, to salvage another child.”¹⁸³ Fearing liability for performing such nontherapeutic and highly invasive procedures, doctors and hospi-

175. Tamar-Mattis, *supra* note 136, at 93.

176. MEYERS, *supra* note 83, at 167. “The courts are the final arbiters of the child’s best interests.” *Id.*

177. Tamar-Mattis, *supra* note 136, at 93; *see also* CANTOR, *supra* note 14, at 132–33; Rosato, *supra* note 139, at 53.

178. Tamar-Mattis, *supra* note 136, at 93.

179. CANTOR, *supra* note 14, at 133.

180. *See* Tamar-Mattis, *supra* note 136, at 93. Other categorical exceptions to parental choice generally include abortion, withholding or withdrawing of life support, and female genital mutilation (often referred to as “female circumcision”). *See* CANTOR, *supra* note 14, at 132; Povenmire, *supra* note 138, at 89. Furthermore, commentators have argued that neonatal male circumcision and genital-normalizing surgery of intersex children should qualify as categorical exceptions to the parental authority model of medical decision making. *See* Povenmire, *supra* note 138, at 89; Tamar-Mattis, *supra* note 136, at 62.

181. Tamar-Mattis, *supra* note 136, at 94.

182. CANTOR, *supra* note 14, at 75–76.

183. *Id.* at 76.

als began to demand judicial approval before proceeding to transplant an organ from a child or otherwise incapacitated donor.¹⁸⁴ Subsequently, most courts have held that the parental authority model is inappropriate in this context, and that judicial approval is required to authorize such organ transplants.¹⁸⁵

Another categorical exception to the parental authority model of medical decision making is sterilization of mentally incompetent children.¹⁸⁶ This area of law is even more settled and restrictive than the law regarding organ donation, primarily stemming from the “history of the abusive use of sterilization as a eugenic tool to prevent procreation by those deemed socially unfit.”¹⁸⁷ As sterilization of mentally incompetent children and adults gradually fell out of favor, a development brought on in part by the collapse of the eugenics movement and the recognition of procreative choice as a fundamental right, courts became increasingly concerned about the potential conflict of interest facing parents seeking sterilization of their mentally incompetent children.¹⁸⁸ Because “much of the burden of an unwanted pregnancy would fall on” the parents, their “desire to avoid such a situation may interfere with their ability to consider the child’s interests independently.”¹⁸⁹ Today, the vast majority of jurisdictions hold that courts alone have the legal authority to consent to the sterilization of a mentally incompetent person.¹⁹⁰

b. Common Characteristics Underlying the Existing Categorical Exceptions

Although independent legal doctrines, the areas of child organ donation and sterilization share three discreet, substantive characteristics that together may justify removing a medical decision from the general presumption of parental discretion. These procedures are (1) nontherapeutic in nature, (2) pose significant risk of parental conflict of interest, and (3) threaten to substantially impair the child’s fundamental rights.¹⁹¹ If a procedure sought by parents on behalf of a child meets these three criteria, it may be necessary to remove the ability to authorize that pro-

184. *Id.*; Tamar-Mattis, *supra* note 136, at 94.

185. Tamar-Mattis, *supra* note 136, at 94.

186. *Id.* at 96.

187. CANTOR, *supra* note 14, at 79. During the first few decades of the twentieth century, “scientific and popular theories of eugenics justified the sterilization of tens of thousands of mentally ill and developmentally disabled people.” Tamar-Mattis, *supra* note 136, at 96. In *Buck v. Bell*, the Supreme Court stamped these practices with the seal of constitutional approval with Justice Holmes’ infamous declaration that “[t]hree generations of imbeciles are enough.” 274 U.S. 200, 207 (1927).

188. See Tamar-Mattis, *supra* note 136, at 96; see also HAAVIK & MENNINGER, *supra* note 167, at 124 (“Judges are no longer viewing sterilization [of mentally incompetent persons] as a way to save society from decline, and they are giving more importance to the rights of the individual to be sterilized.”); Savell, *supra* note 42, at 1120 (“Eugenic theory has been roundly discredited as scientifically invalid and is widely regarded as morally repugnant.”).

189. Tamar-Mattis, *supra* note 136, at 96.

190. CANTOR, *supra* note 14, at 79.

191. See Tamar-Mattis, *supra* note 136, at 97–98.

cedure from the exclusive realm of parental authority and require judicial oversight under the doctrine of *parens patriae* to protect the rights of the child involved.¹⁹² Especially in the context of disabled children—as the two categorical exceptions discussed above usually are—an adversarial proceeding presided over by a neutral judge may be the best forum to ensure that the child’s interests and rights are acknowledged and protected.¹⁹³

i. Nontherapeutic in Nature

The first factor that, together with the other two factors, may justify the recognition of a categorical exception to the presumption of parental authority exists where a desired procedure is nontherapeutic in nature.¹⁹⁴ A procedure can be defined as therapeutic if its purpose is “to cure, alleviate, remove or lessen the symptoms of, or prevent or reduce the possibility of contracting any disorder or malfunction of the human . . . body.”¹⁹⁵ In contrast, elective medical procedures, such as “cosmetic treatment, the termination of pregnancy, castration, sterilization, artificial insemination, embryo transplants, treatments for experimental and research purposes and the removal of organs, skin or bone marrow from a living donor,” are considered nontherapeutic.¹⁹⁶ Such procedures are not implemented to cure or improve an existing disease or medical condition of the person being treated.¹⁹⁷ Furthermore, “[t]herapy addresses a condition of a patient; it does not impede normal development.”¹⁹⁸ Parental authority “to consent to surgical intrusions upon the person of the minor or ward is limited to the power to consent to medical ‘treatment.’”¹⁹⁹

The cases of child organ donation and child sterilization illuminate this distinction between therapeutic medical treatment and nontherapeutic procedures. Child organ donation is considered nontherapeutic, as it is not implemented in order to improve an existing condition of the child-donor, but rather to benefit the prospective organ recipient.²⁰⁰ Likewise, sterilization of a cognitively disabled child for the purposes of preventing

192. See *id.* at 98.

193. See CANTOR, *supra* note 14, at 72.

194. See Tamar-Mattis, *supra* note 136, at 98.

195. Todd Martin, *Patentability of Methods of Medical Treatment: A Comparative Study*, 82 J. PAT. & TRADEMARK OFF. SOC’Y 381, 382 (2000).

196. *Id.* at 382 & n.11 (citation omitted).

197. *Id.* at 382.

198. Bersani, *supra* note 53, at 521.

199. Little v. Little, 576 S.W.2d 493, 495 (Tex. Civ. App. 1979). The court defined “treatment,” in the “broadest” sense, as limited to “the steps taken to effect a cure of an injury or disease.” *Id.* (citation omitted). See also MEYERS, *supra* note 83, at 171 (“The patient’s best interests are served by productive or beneficial treatment.”).

200. See Tamar-Mattis, *supra* note 136, at 94 (noting that organ donation is “a medical procedure that offers no medical benefit to the child”).

menstruation or future pregnancy is nontherapeutic,²⁰¹ as menstruation is a normal aspect of physical development and a future pregnancy is not a presently existing medical condition.²⁰² When parents request a nontherapeutic procedure on behalf of a minor, courts are more likely to step in to protect the child.²⁰³

ii. Significant Potential for Parental Conflict of Interest

A second factor that may justify the removal of a category of medical intervention from the parental authority model is the presence of a significant potential for parental conflict of interest.²⁰⁴ As discussed above, parental authority to consent to medical treatment on behalf of a child is based on a presumption that parents generally make decisions that are in the best interests of their children.²⁰⁵ This presumption may no longer apply, however, where “the needs of the parent are so pressing that they may interfere with independent evaluation of the child’s best interest, and skew the decision to proceed” with a particular medical procedure.²⁰⁶ Where, in light of the circumstances, it cannot be presumed that the parents’ interests are identical to those of the child on whose behalf the procedure is sought, a substantial risk of a parental conflict of interest exists.²⁰⁷

Furthermore, the likelihood of parental conflict of interest may increase where the child at issue is cognitively disabled, as “a family’s lifestyle and resources may be intertwined with a disabled child’s medical fate,” thus potentially interfering with reasonable parental decision making.²⁰⁸ In addition, “parents may share common social prejudices against the retarded and common misconceptions about retarded children’s po-

201. See Savell, *supra* note 42, at 1126 (remarking that the Supreme Court of Canada has held that sterilization for contraceptive purposes is nontherapeutic because it is not “necessary to protect the mental or physical health of a person”). The Supreme Court of Canada has ruled that it is unlikely that sterilization for purely contraceptive purposes could ever be in the best interests of an incompetent individual. *Id.*

202. See Marcus, *supra* note 47, at 616 (“The argument that menses would be messy or that [Ashley] required a prophylactic mastectomy for fibrocystic disease cannot seriously be considered as medical indications for her surgery.”).

203. See Tamar-Mattis, *supra* note 136, at 98.

204. See Rosato, *supra* note 139, at 43; Alyssa Connell Lareau, Note, *Who Decides? Genital-Normalizing Surgery on Intersexed Infants*, 92 GEO. L.J. 129, 142 (2003) (“In cases where parents and doctors agree, deference to parental decisionmaking can be overcome if it is shown that the parent decisionmaker has a conflict that has impaired his or her ability to consider the best interests of the child.”).

205. See *supra* Part IV.A.

206. Tamar-Mattis, *supra* note 136, at 100.

207. See CARLSON & DORFMAN, *supra* note 2, at 27 (describing the potential parental conflict of interest that exists in child sterilization cases).

208. CANTOR, *supra* note 14, at 71; see also Ouellette, *supra* note 13, at 231–32 (arguing that “when the parents’ interests ‘cannot be presumed to be identical to those of the child,’” as is often the case with child sterilization and sibling organ donation, “[t]he risks to the child are so great . . . that the parents lose the benefit of the presumption that they are acting in their child’s best interests, and instead, must prove that the desired procedures are appropriate for their child” (quoting *In re Hayes*, 608 P.2d 635, 640 (Wash. 1980))).

tential for successful adjustment to their circumstances.”²⁰⁹ Where this substantial potential for parental conflict of interest is present, the state has a particularly strong interest in intervening to protect the child from unnecessary medical procedures.²¹⁰

The existing categorical exceptions of child organ donation and child sterilization exemplify the type of underlying parental conflict of interest that may justify judicial review. In the context of child organ donation, the intended recipient of the donated tissue is usually a sibling or close relative.²¹¹ Thus, the parent “is then inevitably faced with the tension between a strong incentive to salvage the donee’s life . . . and a dedication to the interests and well-being of the incapacitated potential donor.”²¹² Likewise, in the context of child sterilization, a parent may be overwhelmed at the prospect of supervising the disabled child’s sexual activity, or even the possibility of having to raise a grandchild that the disabled child is unable to parent.²¹³ The presumption of parental authority should no longer be controlling in regards to categories of medical procedures where parental conflict of interest such as these arise.²¹⁴

iii. Threat of Substantial Impairment to a Fundamental Right

Finally, the third factor that may justify a categorical exception is where the requested procedure threatens to substantially impair the child’s fundamental rights.²¹⁵ “Parental authority to make medical decisions has limits when the decision . . . compromises the child’s fundamental rights.”²¹⁶ The Supreme Court has stated that a child’s constitutional rights do not “magically” come into being when the child reaches legal adulthood; rather, “[m]inors, as well as adults, are protected by the Constitution and possess constitutional rights.”²¹⁷ Invasive medical procedures implicate one of the most sacred fundamental rights of all: the right to bodily integrity.²¹⁸ This right, which guarantees freedom from “unnecessary bodily invasion” and is “part of the broader interest in preserving personal dignity,” attaches fully even to those who have never been competent, including profoundly disabled children.²¹⁹

209. CANTOR, *supra* note 14, at 71.

210. Ouellette, *supra* note 13, at 231–32.

211. CANTOR, *supra* note 14, at 72.

212. *Id.*

213. *Id.*

214. Tamar-Mattis, *supra* note 136, at 100.

215. See Benson, *supra* note 137, at 38; Rosato, *supra* note 139, at 43.

216. Tamar-Mattis, *supra* note 136, at 91.

217. Povenmire, *supra* note 138, at 101 (quoting *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 74 (1976)).

218. See *supra* Part III.

219. CANTOR, *supra* note 14, at 37–38; see also *supra* Part III.C.

Whereas other fundamental rights may be implicated depending on the nature of the intervention,²²⁰ the fundamental right to bodily integrity is implicated by any nonconsensual medical procedure.²²¹ On the one hand, minor procedures—even if nontherapeutic, such as preventative vaccinations²²²—will generally not warrant overriding the presumption of parental medical decision-making authority because of the relatively minor degree of the threatened invasion to the child’s bodily integrity rights.²²³ Neither will *necessary* medical treatment warrant judicial intervention, as the child’s consent to bodily invasion is presumed where a medical procedure is necessary to treat an existing medical condition or to save the child’s life.²²⁴ The fundamental right to bodily integrity is severely threatened, however, by any unnecessary, highly invasive, and irreversible medical procedure requested by a parent on behalf of a child.²²⁵ In such cases, the child’s interest in preserving his or her bodily integrity may outweigh the parent’s interest in making medical decisions on behalf of the child.²²⁶

The well-settled categorical exceptions of child organ donation and child sterilization illustrate this point, as both types of procedures threaten a child’s fundamental rights. Child organ donation constitutes “an unnecessary invasion of bodily integrity that may result in more harm than benefit for the child.”²²⁷ In addition to compromising a child’s fundamental right to bodily integrity, sterilization also violates the child’s fundamental right to procreate.²²⁸ Where a child’s fundamental rights are implicated by a nontherapeutic medical procedure, the best way to ensure protection of these rights is through judicial review of the medical decision-making process.²²⁹

3. *The “Best Interests” Standard*

When a category of parental medical decision making is stripped of the presumption of parental authority and subjected to judicial review under the doctrine of *parens patriae*, as in the cases of child organ dona-

220. For example, the fundamental right to procreate is implicated where parents seek to have a child sterilized. *See infra* note 265.

221. *See* Tamar-Mattis, *supra* note 136, at 91.

222. *See* Kristi L. Kirschner et al., *Ashley X*, 86 AM. J. PHYSICAL MED. & REHABILITATION 1023, 1026 (2007) (noting that prophylactic interventions, such as immunizations, are widely acceptable because the benefits are believed to be very high and the risks are believed to be very low).

223. *See* Tamar-Mattis, *supra* note 136, at 91 (noting that the fact that a surgery is nonconsensual does not, in itself, “disqualify the parents from serving as decision-makers”); *see also* CANTOR, *supra* note 14, at 30 (arguing that only when bodily integrity is “egregiously invaded . . . is core human dignity violated”).

224. *See* Povenmire, *supra* note 138, at 102.

225. *See* Tamar-Mattis, *supra* note 136, at 91.

226. *See id.* at 93.

227. *Id.* at 100.

228. Beh & Diamond, *supra* note 129, at 50 n.236 (quoting *In re Romero*, 790 P.2d 819, 821 (Colo. 1990)); *see also* Rosato, *supra* note 139, at 60; Tamar-Mattis, *supra* note 136, at 100.

229. *See* Tamar-Mattis, *supra* note 136, at 100–01.

tion or sterilization, reviewing courts almost always apply a strict best interests standard.²³⁰ The best interests standard is an objective analysis in which the court weighs the potential benefits a child will receive from a proposed procedure—such as cure or improvement in an existing medical condition or alleviation of suffering and pain—against the potential burdens imposed by the treatment—including potential pain, humiliation, risk of harm, and invasion to bodily integrity—to decide whether a proposed medical procedure is in the child’s best interests.²³¹ In this context, only if the court finds by clear and convincing evidence that a procedure is in the child’s best interest will it grant its approval.²³² The court should ask “what a reasonable person with the characteristics of the incompetent would have done under similar circumstances,”²³³ recognizing that “if a never competent patient were to become miraculously competent, then he or she would want medical decisions to be based on the patient’s interests as assessed by a reasonable person.”²³⁴ Furthermore, the best interests analysis is to focus entirely on the potential benefits and detriments to the child-patient, as opposed to potential benefits and detriments to the caregivers or other third parties.²³⁵ Courts have repeated-

230. See CANTOR, *supra* note 14, at 132; HAAVIK & MENNINGER, *supra* note 167, at 140; MEYERS, *supra* note 83, at 310 (noting that best interests “is the standard all courts have applied to decide upon treatment or nontreatment” when the wishes of the patient cannot be determined). When courts intervene to make medical decisions on behalf of the mentally incompetent, they generally use either a best interests analysis or the substituted judgment test. Kraus, *supra* note 122, at 343. The substituted judgment test, usually applied in cases where the patient was previously competent, asks the court to make a decision consistent with what the patient would make if competent, based on evidence of the patient’s intent from before he or she became incompetent. *Id.* at 343. Courts have almost universally rejected the substituted judgment test in the context of the never-competent—such as severely developmentally disabled children—because the never-competent have “no articulable judgment to be substituted.” CANTOR, *supra* note 14, at 104–05 (quoting Truselo v. Carroll, 846 A.2d 256, 271 (Del. Fam. Ct. 2000)); see also *In re Martin*, 538 N.W.2d 399, 407 (Mich. 1995) (noting that, in the context of medical decision making, the best interests test should be applied where there is no subjective evidence of the individual patient’s wishes, such as statements made by the patient). Even where courts erroneously apply a substituted judgment test to profoundly disabled children, “the standard inevitably gets transformed into a best-interests approach.” CANTOR, *supra* note 14, at 42. For a thorough analysis of the debate between the best interests approach and substituted judgment approach, specifically in the context of profoundly developmentally disabled children such as Ashley X, see generally Ryan, *supra* note 17.

231. MEYERS, *supra* note 83, at 171.

232. See Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37, 71–72 (2004) (noting that the “clear and convincing evidence” standard is well-settled and constitutionally required); see also, e.g., Benson, *supra* note 137, at 49.

233. Paul B. Solnick, *Proxy Consent for Incompetent Non-Terminally Ill Adult Patients*, 6 J. LEGAL MED. 1, 15 (1985).

234. CANTOR, *supra* note 14, at 107. It is certainly true that the best interests standard may not always be able to ascertain the “true, unexpressed wishes of the patient,” because the patient “may not be a ‘reasonable’ person, or want done what most ‘reasonable’ people would under the circumstances.” MEYERS, *supra* note 83, at 171. Despite its shortcomings, however, the best interests standard is widely regarded as the best and “only decision-making standard available in the circumstances” for the never-competent patient, because “it prevents a situation where no decision is made, or others make the decision by default, thereby diminishing the patient’s right to self-determination, and it represents a genuine choice, reasonably imposed, in an effort to do what the patient would, presumably, want done.” *Id.* (citations omitted).

235. CANTOR, *supra* note 14, at 143.

ly held that third-party interests—including those of parents—are not to be factored into the best interests analysis.²³⁶

In the context of profoundly developmentally disabled children, the invocation of the best interests test is appropriate for two reasons. First, the doctrine of *parens patriae*, under which courts are empowered to intervene in these situations,²³⁷ is essentially the duty of the state to uphold the best interests of the child.²³⁸ Thus, “whenever government intervenes to scrutinize a surrogate’s medical determination on behalf of a helpless person and whenever a problematic medical issue is reserved for judicial resolution, that helpless person’s interests are ostensibly the key factor.”²³⁹ Second, the best interests of the patient are considered “an appropriate and humane default standard for surrogate decision making where never competent persons cannot make binding personal choices.”²⁴⁰ In other words, it is appropriate for courts to assume that “any human being, no matter how mentally disabled, would want to have their own interests protected and promoted.”²⁴¹

The best interests standard has typically been applied to both child organ donation and child sterilization cases. In the context of child organ donation, courts often look at factors such as “expert medical and psychological testimony about the effects of surgery, evidence of the likelihood of success of the procedure, and evidence of the unavailability of other practical options” in reaching their best interests determinations.²⁴² In considering whether sterilization is in a disabled child’s best interests, courts commonly look to factors such as “the workability of less intrusive measures, the medical necessity, risks and benefits of the procedure, and the possibility of future competence of the ward.”²⁴³ As is made clear by these examples, the bottom line of the best interests analysis is whether the benefits of the proposed medical procedure outweigh the detriments: “whether the net welfare of the profoundly disabled patient would be advanced by the performance of the contemplated procedure.”²⁴⁴

236. *Id.* at 139. “Justice does not demand that a caretaker be free of all onerous burdens.” *Id.* For an in-depth analysis of the role of third-party interests in the best interests calculus, see *id.* at 136–48. See also MEYERS, *supra* note 83, at 172 (noting that best interests is a “patient-centered standard” that examines “what is best for the patient,” not a “socially-centered standard” that looks at “what is best for others” (citation omitted)). “Quality of life should not be confused with the value or worth of someone’s life to others, to society, or based on the standards set by others.” *Id.*

237. See *supra* Part IV.B.1.

238. See CANTOR, *supra* note 14, at 102 (noting that “the watchword for *parens patriae* jurisdiction is the best interests of the disabled person”).

239. *Id.*

240. *Id.* at 29.

241. *Id.*

242. Tamar-Mattis, *supra* note 136, at 95.

243. *Id.* at 97.

244. CANTOR, *supra* note 14, at 106.

V. RECOMMENDATION: APPLYING THE RIGHT TO BODILY
INTEGRITY AND THE CATEGORICAL EXCEPTION
FRAMEWORK TO PARENTAL REQUESTS FOR
NONTHERAPEUTIC GROWTH ATTENUATION

What if the fundamental issue driving the Ashley Treatment is this sentiment—the fact that society is uncomfortable with adults who have cognitive disabilities? If so, should health care professionals ever sanction or be complicit in using medical treatments to alter the bodies of people with disabilities to make them more acceptable, more lovable, or more comfortable to others? And if not, should there be prohibitions on certain types of medical treatments for children and those who cannot consent for themselves?²⁴⁵

The preceding analysis in this Note highlights that, although the parental authority model usually grants parents broad discretion to make medical decisions on behalf of children, the application of that model to certain categories of medical decisions is problematic due to the nontherapeutic nature of the procedure, the significant risk of parental conflict of interest, and the threat to the child’s fundamental rights—in particular the right to bodily integrity. When parents request procedures that are characterized by these three substantive features, the doctrine of *parens patriae* requires that courts intervene in the parental decision-making process to protect the rights of children by determining whether the procedure is in the child’s best interests.

Building off of the above analysis, this Part demonstrates that the Ashley Treatment and similar growth-attenuating procedures pose the same risks justifying the other well-settled categorical exceptions to the parental discretion framework. Thus, nontherapeutic growth attenuation should be recognized as a categorical exception to the parental authority paradigm, and courts should intervene when parents seek nontherapeutic growth attenuation on behalf of their disabled children. This Part then argues that a court applying the best interests standard must balance the potential benefits of such treatment against the detriments, the most significant of which is the threatened extreme and irreversible invasion of the child’s fundamental right to bodily integrity. Finally, this Part concludes that the *essence* of the fundamental right to bodily integrity—the “right to be left alone”—is the right to normal, healthy development. Thus, a court applying the best interests test to parental requests for nontherapeutic growth attenuation should rarely—if ever—find that nontherapeutic growth attenuation is in the best interests of the child.

245. See Kirschner et al., *supra* note 222, at 1028.

A. *Judicial Intervention: Nontherapeutic Growth Attenuation as a Categorical Exception to the Parental Decision-Making Authority Presumption*

The Ashley Treatment and similar nontherapeutic, growth-attenuating procedures should be recognized as a categorical exception to the general presumption of parental medical decision-making authority because the primary rationales underlying other recognized categorical exceptions—for example, child organ donation and child sterilization—equally apply to parental requests for growth attenuation on behalf of profoundly developmentally disabled children.²⁴⁶ Specifically, growth-attenuating procedures similar to those used in the Ashley Treatment are nontherapeutic, involve strong potential for substantial parental conflict of interest, and severely threaten the profoundly developmentally disabled child's fundamental rights, particularly the fundamental right to bodily integrity. "Where there are strong indications that parental instincts and medical judgment are not sufficient to protect the interest of the child, we can look to the existing categorical exceptions for a model of decision-making that ensures independent consideration of the child's interests."²⁴⁷ Because the case of Ashley X is, so far, the only documented instance of this type of growth-attenuating intervention,²⁴⁸ the following analysis will discuss these three factors through the lens of that case.

1. *Nontherapeutic in Nature*

The type of growth-attenuating intervention performed on Ashley X is essentially nontherapeutic in nature.²⁴⁹ Rather than treating an existing disease of medical condition, growth attenuation irreversibly impedes normal, healthy development.²⁵⁰ Ashley X suffered from the condition of static encephalopathy,²⁵¹ but growth attenuation did not address that condition.²⁵² The asserted primary purposes of Ashley X's growth attenuation—to "[i]ncrease mobility thru [sic] [the] caregiver" and "[i]ncrease

246. See CARLSON & DORFMAN, *supra* note 2, at 28 (concluding the WPAS report by stating that "judicial review of proposed procedures like the 'Ashley Treatment' is absolutely necessary").

247. Tamar-Mattis, *supra* note 136, at 98.

248. See CARLSON & DORFMAN, *supra* note 2, at 12 ("As stated by Ashley's parents and her doctors, to their knowledge, this was the first time that these procedures and interventions had been combined to achieve that goal of keeping a person with a developmental disability from fully developing.").

249. Bersani, *supra* note 53, at 521; Clark & Vasta, *supra* note 19 ("Ashley had a surgical procedure that involves pain and risks and was nontherapeutic.").

250. Bersani, *supra* note 53, at 521; see also George C. Denniston, *Human Rights Advances in the United States, in BODILY INTEGRITY AND THE POLITICS OF CIRCUMCISION: CULTURE, CONTROVERSY, AND CHANGE* 189, 199 (George C. Denniston et al. eds., 2006) (noting that "the right to an intact body" is a "basic human right").

251. See *supra* note 19–22 and accompanying text.

252. See Ouellette, *supra* note 13, at 210 n.7 (noting that "Ashley's growth was not an injury or disease," and that the Ashley Treatment "did not effect a cure of any medical condition").

[the] chance of living at home”²⁵³—clearly are not related to the treatment of an existing disease or condition.

Furthermore, the other aspects of the Ashley Treatment—the hysterectomy and mastectomy—were prophylactic, and thus decidedly nontherapeutic, in nature. The primary stated purpose for the mastectomy was to “[e]liminate discomfort caused from large breasts, laying down or in supportive harness,” and the primary stated purpose for the hysterectomy was to “[e]liminate menstrual pain [and] cramps.”²⁵⁴ As Ashley had neither developed large breasts nor begun menstruating at the time of the surgeries,²⁵⁵ both of these procedures were entirely nontherapeutic in that they did not treat an existing disease or medical condition. The typical presumption of parental medical decision-making authority is inappropriate where parents—such as Ashley’s—choose highly invasive, extreme, and irreversible medical procedures on behalf of their child for nontherapeutic reasons.²⁵⁶

2. Significant Potential for Parental Conflict of Interest

The type of growth-attenuating intervention performed on Ashley X carries with it a strong potential for significant conflict of interest between the parents and the child.²⁵⁷ Much like parents requesting that a child donate an organ to an ill sibling or undergo sterilization, Ashley’s parents were posed to reap enormous benefits by altering Ashley’s body.²⁵⁸ The growth-attenuating intervention would prevent them from having to care for “a profoundly needy adult-sized being,” or suffer as much bodily strain when moving Ashley.²⁵⁹ Because the procedures would increase the probability that they could care for Ashley without the assistance of numerous outside caregivers, “[t]hey could keep strangers out of their home.”²⁶⁰ This would also enable them to possibly “spend more time and money on their ‘healthy’ children because Ashley would require less physical attention.”²⁶¹ In addition, by increasing the

253. Ashley’s Parents, *Flowchart*, *supra* note 7 (euphemistically referring to growth attenuation as “Sizing for Wellness”).

254. *Id.* Some have pointed out that these supposed justifications are, in reality, arguments of convenience. See, e.g., S. Matthew Liao, Julian Savulescu & Mark Sheehan, *The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making*, HASTINGS CENTER REP., Mar.–Apr. 2007, 16, 18 (noting, for example, the absurdity of Ashley X’s parents’ choosing a mastectomy to lessen the discomfort to Ashley of securing her in her wheelchair with a chest strap versus finding a chest strap that would better accommodate Ashley’s potentially large future breasts).

255. See Gunther & Diekema, *supra* note 3, at 1014 (noting that the only signs of puberty Ashley exhibited were “a 1-year history of pubic hair development and 3-month history of breast budding”).

256. See Ouellette, *supra* note 13, at 244.

257. *Id.* at 233.

258. *Id.*; see also Lynn E. Lebit, Note, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine*, 7 J.L. & HEALTH 107, 108 (1992) (noting that whereas nontherapeutic interventions “are of no physical benefit to the incompetent person,” these procedures “may benefit . . . the guardians of the incompetent individual”).

259. Ouellette, *supra* note 13, at 233.

260. *Id.*

261. *Id.* (footnote omitted).

likelihood that they could care for Ashley at home over the long-term, they would avoid experiencing the sense of guilt and loss suffered by many parents who make the difficult decision to institutionalize their disabled children.²⁶² Furthermore, the mastectomy and hysterectomy would prevent Ashley's parents from having "to deal with her menstrual blood, or see their 'pillow angel' develop adult breasts that they saw as incompatible with her mental development."²⁶³ The presence of these and many more potential benefits to parents seeking nontherapeutic growth attenuation for their disabled children creates a substantial parental conflict of interest that justifies judicial intervention to protect the children involved.²⁶⁴

3. *Threat of Substantial Impairment to the Child's Fundamental Right to Bodily Integrity*

Nontherapeutic growth attenuation threatens to severely and irreversibly impair the profoundly developmentally disabled child's fundamental rights—specifically, the right to bodily integrity.²⁶⁵ As discussed in Part III, the fundamental right to bodily integrity is, in essence, the right to be left alone.²⁶⁶ What could be a greater violation of this principle of the "inviolability" of the body²⁶⁷ than to permanently terminate a child's normal, healthy physical development?

Because severely developmentally disabled children are unable to consent to medical procedures, parents are generally empowered to consent on the child's behalf,²⁶⁸ as parental choices are usually presumed to be in the child's best interests.²⁶⁹ Although this presumption should apply when a particular medical treatment is necessary to save the child's life or treat an existing medical condition or disease, a request for nontherapeutic growth attenuation—a procedure that offers no curative value but threatens to severely and irreversibly compromise a child's fundamental right to bodily integrity—should be subject to a judicial determination that the procedure is truly in the child's best interest.²⁷⁰ Just as the absence of consent from a competent adult is all that is required to preserve the adult's bodily integrity, the absence of consent from a child—even a

262. *Id.*

263. *Id.*

264. *See id.* at 233–34.

265. In addition to the invasion of the child's fundamental right to bodily integrity, the hysterectomy performed on Ashley violated her fundamental right to procreate. *See* Tamar-Mattis, *supra* note 136, at 96 (noting that the fundamental right to procreate is lost through sterilization).

266. *See supra* note 91 and accompanying text.

267. *See supra* note 94 and accompanying text.

268. Tamar-Mattis, *supra* note 136, at 79.

269. *See* CANTOR, *supra* note 14, at 70; *supra* Part IV.A.

270. *Cf.* Benson, *supra* note 137, at 50 ("The intersex child's well-established fundamental right to bodily integrity provides the framework for a halt on genital surgeries."); Povenmire, *supra* note 138, at 102–03 (arguing for the invocation of *parens patriae* judicial review over parental requests for male infant circumcision).

severely cognitively disabled child incapable of offering consent—should be enough to preserve the child’s bodily integrity unless a procedure is found to be in the child’s best interests.²⁷¹

B. Best Interests Analysis: Weighing the Potential Benefits and Detriments of Nontherapeutic Growth Attenuation

Because parental requests for nontherapeutic growth attenuation of profoundly developmentally disabled children implicate the three factors that justify the recognition of categorical exceptions to the parental medical decision-making authority presumption, courts have a duty under the doctrine of *parens patriae* to intervene in these cases. As a preliminary matter, it is worth noting that physicians and hospitals will most certainly affirmatively seek judicial approval of all future parental requests for the so-called Ashley Treatment or nontherapeutic growth attenuation of cognitively disabled children due to the combined factors of the widespread publicity of Ashley X’s case,²⁷² the public outcry,²⁷³ and the WPAS settlement with Seattle Children’s Hospital requiring judicial review of all future parental requests for such interventions.²⁷⁴ Thus, although it has been argued that a legislative mandate is necessary to get these cases in the courtroom door,²⁷⁵ a legislative response is probably not necessary, let alone preferable or permissible.²⁷⁶ Rather, physicians and hospitals, aware of the potential legal repercussions of administering such procedures and fearing later lawsuits, will seek declaratory judgments approving of the interventions before proceeding with the Ashley Treatment or similar nontherapeutic, growth-limiting procedures.²⁷⁷

Once these cases are brought before a judge, the doctrine of *parens patriae* dictates that the court determine whether the nontherapeutic growth attenuation, along with any additional requested prophylactic procedures (such as mastectomy or hysterectomy), are in the best interests of the disabled child.²⁷⁸ To make this determination, the court must weigh the potential benefits the child would receive as a result of under-

271. See Povenmire, *supra* note 138, at 102.

272. See Ashley’s Mom & Dad, *Ashley Treatment Summary*, *supra* note 36, at 3 & n.2 (noting the “extensive and worldwide” coverage of their daughter’s case, as evidenced by the fact that it “topped the Health section of Google News between January 5th and January 8th” and the fact that “there have been more than 600 related articles worldwide”).

273. See *supra* Part II.B.

274. See *supra* note 67 and accompanying text.

275. See McDermott, *supra* note 16, at 431.

276. There are two main reasons why legislative mandate of judicial review is not the best recourse. First, it would potentially take a long time to build enough political support to motivate legislatures to write such a bill, especially in regards to such a complicated medical intervention that would affect a relatively small percentage of the population. Cf. Tamar-Mattis, *supra* note 136, at 107 (making this argument in the context of genital-normalizing surgeries on intersex children). Second, legislatures have traditionally been hesitant to legislatively regulate medical decisions. See *id.*

277. Cf. *id.* at 107–08 (arguing that “a statute requiring judicial approval of genital-normalizing surgeries on children” is not necessary because “doctors themselves will bring this question to court”).

278. See *supra* Part IV.B.3.

going nontherapeutic growth attenuation against the potential detriments to the child.²⁷⁹ Only if the court finds by clear and convincing evidence that the intervention is in the child's best interests—that the potential benefits clearly outweigh the harms—will it authorize the procedure.²⁸⁰ In addition, when parents request a *nontherapeutic* procedure, courts assume an “even more child-protective stance” and require especially strong evidence that a procedure is in the child's best interests.²⁸¹ In the context of the profoundly disabled child, the best interests standard ensures that the child “will benefit from reasoned choice—consideration of the possible gains or harms of a contemplated medical procedure—thereby promoting [the child's] constitutionally based interests in well-being, bodily integrity, and dignity.”²⁸²

1. *Potential Benefits to the Child*

As discussed throughout this Note, Ashley X's parents, physicians, and supporters have asserted numerous alleged benefits that would accrue to profoundly developmentally disabled children through nontherapeutic growth attenuation.²⁸³ These asserted benefits, however, are all either social²⁸⁴ or prophylactic in nature.²⁸⁵ None of the parents' or physicians' proffered benefits address the treatment of an existing disease or medical condition.²⁸⁶ Nonetheless, it is conceivable that profoundly developmentally disabled children could benefit in some ways from interventions similar to the Ashley Treatment. Perhaps permanently arresting the growth of these children could to some extent improve their quality of life by making it easier to include them “in the typical family life and activities that provide [them] with needed comfort, closeness, security and love,” such as “meal time, car trips, touch, [and] snuggles.”²⁸⁷ Furthermore, even if many of the purported “benefits” to the child are, in reality, benefits to the caregivers, it is possible that by reducing the caregiver's burden, the child could benefit from “enhanced care.”²⁸⁸

279. See *supra* note 231 and accompanying text.

280. See *supra* note 232.

281. Svoboda et al., *supra* note 97, at 88.

282. CANTOR, *supra* note 14, at 41.

283. See *supra* Parts II, V.A.1.

284. Ouellette, *supra* note 13, at 238.

285. For example, Ashley's parents alleged that the elimination of the chances of breast or uterine cancer were “benefits” of the mastectomy and hysterectomy. See Ashley's Parents, *Flowchart*, *supra* note 7; cf. Svoboda et al., *supra* note 97, at 81 (noting, ironically, that if a guardian requested that an incompetent adult “undergo surgery to remove a normal healthy, non-diseased, uninjured part of the body simply . . . as a prophylactic measure to avoid some infinitesimal risk of disease to that part of the body,” “doctors and lawyers would inform [the guardian] without hesitation that [his or her] request is inappropriate and legally unsupportable”).

286. See *supra* Part V.A.1.

287. Ashley's Mom & Dad, *Ashley Treatment Summary*, *supra* note 36, at 4.

288. Posting of George Dvorsky to Sentient Developments, *supra* note 55 (arguing in favor of the “Ashley Treatment”). *Contra* Rosato, *supra* note 139, at 40 (noting that the “burden on the family” is not a “morally justifiable” rationale, because it focuses on “the interests of others” instead of “directly on the patient's interests”).

2. *Potential Harms to the Child*

On the other side of the best interests scale, however, are profound harms and grave risks to the profoundly developmentally disabled child which must be given full consideration by the reviewing court. The Ashley Treatment and similar nontherapeutic, growth-attenuating procedures expose the child to severe and potentially fatal health risks, completely disregard the child's potential for future physical and intellectual development while relying on the caregivers' and physicians' limited understanding of the child's quality of life, and—most significantly—threaten to substantially and irreversibly violate the child's fundamental right to bodily integrity.

First, the high-dose estrogen “therapy”²⁸⁹ administered to permanently arrest the child's growth brings with it the significant risk of deep vein thrombosis, caused by the formation of blood clots deep in the veins that can dislodge and block major arteries leading to the heart or lungs.²⁹⁰ These blockages, known as pulmonary embolisms, can be “fatal in a matter of hours” and are “virtually asymptomatic.”²⁹¹ This threat is even greater for nonambulatory children, such as the profoundly developmentally disabled, whose sedentary conditions put them at an even greater risk.²⁹²

Second, the rationales underlying the Ashley Treatment and similar procedures disregard the child's potential for future physical and intellectual development,²⁹³ and instead rely on a very incomplete, and perhaps incorrect, understanding of the profoundly disabled child's quality of life as experienced by the child.²⁹⁴ Caregivers of profoundly developmentally disabled children have been found to consistently underestimate their children's quality life, and have a limited ability to predict what constitutes a “good” quality of life for a disabled child.²⁹⁵ Furthermore, doctors seeking to administer nontherapeutic growth interventions to profoundly disabled children may claim, as Drs. Gunther and Diekema did, that there is no potential for future cognitive growth and development in these children.²⁹⁶

289. Ashley X's estrogen prescription was “eleven times greater than the standard prescribed oral contraceptive dosage.” Clark & Vasta, *supra* note 19.

290. *Id.*

291. *Id.*

292. *Id.*

293. Bersani, *supra* note 53, at 521.

294. Kirschner et al., *supra* note 222, at 1026, 1028 (explaining that the “use of quality-of-life criteria when making [a] decision on behalf of people who cannot speak for themselves”—such as profoundly developmentally disabled children—is problematic).

295. *See id.* (noting that “numerous studies have demonstrated that health care professionals are not very accurate at predicting what life with disability is like and, indeed, consistently underestimate the quality of life as expressed by people who live with disabilities and chronic conditions”); *see also* Shannon & Savage, *supra* note 11, at 177 (“The parents' projection of Ashley's quality of life may be conflated with the projection of their own or their family's quality of life.”).

296. *See* Gunther & Diekema, *supra* note 3, at 1014 (stating in regard to Ashley X that “there will be no significant future improvement in her cognitive or neurologic baseline”).

On the contrary, “[d]evelopmental skills and abilities of children with pervasive needs . . . can change with time, nurturance, and stimulation, just as they can change for children without disabilities.”²⁹⁷ Thus, describing children such as Ashley X as having the permanent mental age of an infant,²⁹⁸ and then analyzing the child’s best interests through that lens, may “unnecessarily limit expectations for the future and ignores [the child’s] capacity for social and emotional development.”²⁹⁹ Research has shown “abundant evidence that all children are able to learn, that the cognitive capabilities of children with severe motor impairments can be grossly underestimated, and that an ever-improving future for individuals with extensive impairments is achievable.”³⁰⁰ Furthermore, studies have demonstrated a direct link between disabled children’s physical growth and their improved health and social participation.³⁰¹ Thus, underestimating a profoundly developmentally disabled child’s potential for future intellectual development and choosing to permanently terminate the child’s healthy physical development on the basis of that possibly erroneous assumption may actually work to *increase* the likelihood that the child will never reach his or her full cognitive potential.³⁰²

Finally, and most profoundly, the court must weigh the extreme, highly invasive, and irreversible invasion of the child’s fundamental right to bodily integrity. Because a fundamental right is implicated by nontherapeutic, growth-attenuation procedures, the weighing judge “must take the greatest care to ensure that the incompetent’s rights are jealously guarded.”³⁰³ Furthermore, even beyond other implicated rights, when a court must decide whether to approve a medical procedure on behalf of

297. Kirschner et al., *supra* note 222, at 1025.

298. At least one commentator has noted that the task of assigning a “mental age” is primarily based on “guesswork.” Dotinga, *supra* note 75. Though parents and families “crave a diagnosis,” physicians admit that they are “not very good at” estimating mental age. *Id.* This task is especially difficult when a child has no language skills and restricted movement, such as Ashley; in these cases, doctors are “left to simply sit and watch,” and eventually formulate a diagnosis. *Id.* For these reasons, some professionals consider the concept of mental age to be a “failure.” *Id.*; see also Anne McDonald, *The Other Story from a “Pillow Angel,”* HUM. LIFE REV., Fall 2007, at 91, 93 (“Any assessment of intelligence that relies on speech and motor skills cannot conceivably be accurate because the child doesn’t have any of the skills required to undertake testing.”).

299. Kirschner et al., *supra* note 222, at 1025.

300. Bersani, *supra* note 53, at 521.

301. See Kirschner et al., *supra* note 222, at 1026.

302. For a very personal and profound critique of the “Ashley Treatment,” focusing on the failure of parents and doctors to recognize the potential for cognitive development, see generally McDonald, *supra* note 298. The author, also diagnosed with “static encephalopathy” as a child, was eventually taught to communicate as a teenager, and went on to earn college degrees and write and speak extensively on disability issues. *Id.* at 91–92. “Only someone like me who has lain in a cot year after year hoping that someone would give her a chance can know the horror of being treated as if you were totally without conscious thought.” *Id.* at 93.

303. Estate of C.W., 640 A.2d 427, 428 (Pa. Super. Ct. 1994) (quoting *In re Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982)).

an incompetent individual, “the value the state places on protecting that individual’s bodily integrity, above all else, comes to the fore.”³⁰⁴

This Note argues that, at its most basic level, the right to bodily integrity is the *right to healthy development*.³⁰⁵ Looking after the best interests of severely disabled children such as Ashley X involves “more than just making [them] as comfortable as possible. We must also allow [them] to develop naturally.”³⁰⁶ Because of the “sacred” and “inviolable” nature of this right,³⁰⁷ the “incompetent person’s presumptive right against invasion of his or her bodily integrity places the burden on anyone who would infringe that right to prove that it is *necessary* for the incompetent person’s welfare.”³⁰⁸ Thus, in the final analysis, even if parents and physicians can show that a child will benefit in some ways as a result of a nontherapeutic growth attenuation, only where the procedure is *necessary* to the child’s welfare—for example, if it would save the child’s life or improve an existing medical condition or disease—will those benefits outweigh the heavy presumption of preserving the child’s bodily integrity. Therefore, a court reviewing a parental request for nontherapeutic growth attenuation on behalf of a severely developmentally disabled child should rarely—if ever—find the procedure to be in the best interests of the child.³⁰⁹

VI. CONCLUSION

Make sure you ask yourself and your surgeon, more than once: Given the risks, should you ever choose, on behalf of someone else (even your own child), a surgery offered purely for psychological and social reasons? . . . [C]onsider the possibility that, instead of

304. Neff, *supra* note 76, at 341.

305. Cf. Svoboda et al., *supra* note 97, at 83 (arguing that the general presumption of parental authority to consent to medical treatment on behalf of a child does not authorize parents to choose procedures that are likely to “impair [the child’s] healthy development”).

306. Clark & Vasta, *supra* note 19 (citation omitted).

307. See *supra* Part III.A.

308. Svoboda et al., *supra* note 97, at 78 (emphasis added).

309. As previously noted, outright prohibition of nontherapeutic growth attenuation is not a viable option. See *supra* note 46. Although this Note argues that nontherapeutic growth attenuation procedures should almost never be approved on behalf of severely developmentally disabled children, it is possible, albeit unlikely, that a situation could arise where such treatment would meet the standards of the best interest test. For example, if a disabled adolescent was experiencing extremely rapid growth and expected to be much taller than average, hormone therapy to help slow down the rate of growth, without impeding the child’s healthy development in other ways (the child would still reach an adult height and attain full sexual development) should arguably be an option, because such treatment is available for nondisabled children in this context. See Gunther & Diekema, *supra* note 3, at 1014–15 (discussing the once somewhat common and still available—albeit controversial—use of growth attenuating interventions to limit the growth of tall adolescent girls). As illustrated by this example, judicial review is the preferable way to approach the issue of nontherapeutic growth attenuation as judicial application of the best interests test operates to protect the rights of severely developmentally disabled children while still allowing them to have access to the same range of medical options as their nondisabled counterparts.

changing your child's body, we should start expecting others to change their minds.³¹⁰

The above analysis describes the existing legal mechanisms for protecting profoundly developmentally disabled children from unnecessary, extreme, and irreversible medical interventions, and ultimately argues that these mechanisms provide a legal framework for safeguarding the rights of disabled children when parents request the Ashley Treatment or similar nontherapeutic, growth-attenuating procedures. The fundamental right to bodily integrity—essentially, the right to be left alone—fully attaches to severely developmentally disabled children. Though parents generally enjoy broad medical decision-making discretion, courts have a duty under the doctrine of *parens patriae* to protect the best interests of the child by intervening when parents request a procedure that is nontherapeutic in nature, poses a substantial potential for parental conflict of interest, and severely threatens the child's fundamental rights, particularly the right to bodily integrity. Because the Ashley Treatment and similar growth-attenuating interventions involve these three substantive characteristics, judicial review is necessary to protect the child's interests when parents request such procedures. Furthermore, because the immense harms threatened by nontherapeutic growth attenuation—most notably, the severe and permanent invasion of the child's right to bodily integrity by permanently ending the child's healthy physical development—will most likely outweigh any purported benefits, a court should almost always find such procedures to be against the child's best interests.

Unfortunately, due to the failure of Ashley X's parents, physicians, and hospital to take the necessary steps to safeguard her interests, Ashley's right to bodily integrity was afforded no such protection.³¹¹ Ashley's sacrifice is not entirely in vain, however, because it has brought the debate over the care of disabled children to the forefront.³¹² The publicity surrounding the case of Ashley X has ultimately incited an honest, open discussion about the egregious and inexcusable lack of practical support for the families of disabled children.³¹³ “In the end, what might be most distressing about [the Ashley Treatment] . . . is how this solution fails to situate the plight of these parents, struggling to care for their children, in the larger context of a society failure to provide adequate social support in this most admirable of undertakings.”³¹⁴

310. Alice Domurat Dreger, *What to Expect when You Have the Child You Weren't Expecting*, in *SURGICALLY SHAPING CHILDREN* 253, 261 (Erik Parens ed., 2006).

311. See CARLSON & DORFMAN, *supra* note 2, at 25 (noting that “no court order was ever sought, and there was no opportunity for Ashley to have her legal rights represented in this case”).

312. See *id.* at 28 (noting the “continuing dialogue in regards to how society values and respects people with developmental disabilities and their rights”).

313. Kirschner et al., *supra* note 222, at 1025.

314. Jeffrey P. Brosco & Chris Feudtner, *Growth Attenuation: A Diminutive Solution to a Daunting Problem*, 160 *ARCHIVES PEDIATRICS & ADOLESCENT MED.* 1077, 1078 (2006).

The challenges and fears that prompted Ashley's parents' decision to proceed with this intervention—“[f]ears about inadequate and unsafe care, supports, and services available in the community”—are shared by countless families across this country.³¹⁵ Perhaps if Ashley's parents truly believed that she would always receive competent and compassionate care—regardless of whether she was able to remain in their home, and despite her size or sexual development—their concerns would have been alleviated.³¹⁶ Perhaps if they believed their community and government would have supported them, financially and otherwise, they would have reached out for help before choosing a medical path that severely violated their daughter's fundamental right to bodily integrity, leaving her permanently disfigured and ending her healthy physical development. Hopefully, through the public discourse over the case of Ashley X, parents in similar situations will be empowered to reach out for help before seeking such drastic means of mitigating the potentially overwhelming burden of caregiving, and find the courage to admit that it is they—not their disabled children—who are in need of an intervention.³¹⁷

315. See CARLSON & DORFMAN, *supra* note 2, at 28.

316. See Kirschner et al., *supra* note 222, at 1025.

317. Alice Dreger, *Ashley and the Dangerous Myth of the Selfless Parent*, HASTINGS CENTER BIOETHICS F., Jan. 18, 2007, <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=332>.

