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# Shaping Parental Authority Over Children's Bodies

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# Shaping Parental Authority Over Children’s Bodies

By Alicia Ouellette\*

## Abstract

U.S. law treats parental decisions to size, shape, sculpt, and mine children’s bodies through the use of non-therapeutic medical and surgical interventions like decisions to send a child to a particular church or school. They are a matter of parental choice except in extraordinary cases involving grievous harm. This Article questions the assumption of parental rights that frames the current paradigm for medical decisionmaking for children. Focusing on cases involving eye surgery, human growth hormone, liposuction, and growth stunting, I argue that by allowing parents to subordinate their children’s interests to their own, the current paradigm distorts the parent-child relationship and objectifies children. I propose an alternative. Pushing analogies developed in family law and moral philosophy to respect children as complete but vulnerable human beings, I develop a trustee-based construct of the parent-child relationship, in which the parents are assigned trustee-like powers and responsibilities over a child’s welfare and future interests, and charged with fiduciary-like duties to the child. Application of the trustee-based construct separates medical decisions that belong to parents, from decisions that belong to children and those that should be made by a neutral third party.

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# Shaping Parental Authority Over Children's Bodies

## Introduction

U.S. law allows parents extraordinary power over their children's bodies. Parents have used that power to westernize the eyes of their adoptive Asian children,<sup>1</sup> to modify the Downs-typical facial features of their children with Down Syndrome,<sup>2</sup> to inject human growth hormone into healthy children,<sup>3</sup> to enlarge the breasts of or suck the fat from teenagers,<sup>4</sup> to attenuate the growth and remove the reproductive organs of a child with disabilities,<sup>5</sup> and to remove bone marrow from a nine-year-old girl for use by a brother who sexually abused her.<sup>6</sup> To be sure, physicians or surgeons are the ones who physically modify the child's body,<sup>7</sup> but they do so as agents of parents. And in the case of elective interventions, it is the parents who seek out medical or surgical modifications, find a willing provider, and give their consent to size, shape, sculpt, or mine their

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<sup>1</sup> The author heard one father describe having elected this procedure for his young adopted daughter. See also, *Asian Children Undergoing Cosmetic Surgery for 'Westernized' Look*, COSMETIC SURGERY REV., Feb. 5, 2009, available at <http://cosmeticsurgerytoday.wordpress.com/2009/02/05/asian-children-undergoing-cosmetic-surgery-for-westernized-look>; Sandy Kobrin, *Asian Americans Criticize Eyelid Surgery Craze*, WOMEN'S E-NEWS, Aug. 14, 2004, available at <http://www.womensenews.org/article.cfm/dyn/aid/1950>.

<sup>2</sup> See, e.g., S. Kravetz et al., *Plastic Surgery for Persons With Down Syndrome: Parent's Perceptions of Physical, Personal and Social Functioning*, 13 RESEARCH DEVELOPMENTAL DISABILITIES 145 (1992); Len Leshin, *Plastic Surgery in Children with Down Syndrome* (2000), available at <http://www.ds-health.com/psurg.htm>

<sup>3</sup> See Food and Drug Administration, *FDA Approves Humatrope for Short Stature*, FDA TALK PAPER, July 25, 2003, available at [www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html](http://www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html); M. Freemark, Editorial, *Growth Hormone Treatment of 'Idiopathic Short Stature': Not So Fast*, 89 J. OF CLINICAL ENDOCRINOLOGY AND METABOLISM 3138 (2004); David B. Allen & Norman Fost, *hGH for short stature: ethical issues raised by expanded access*, 144 J. PEDIATR. 648 (2004); Linda D. Voss, *Growth hormone therapy for the short normal child: who needs it and who wants it? The case against growth hormone therapy*, 136 J. PEDIATR. 103 (2000).

<sup>4</sup> See, e.g., Diana Zuckerman & Anisha Abraham, *Teenagers and Cosmetic Surgery: Focus on Breast Augmentation and Liposuction*, 43 J. OF ADOLESCENT HEALTH 318 (October 2008); Mary Duenwald, *The Consumer, How Young is Too Young to Have Nose Job and Breast Implants*, N.Y. TIMES, Sept. 8, 2004, available at <http://query.nytimes.com/gst/fullpage.html?res=9405E5D91638F93BA1575AC0A9629C8B63&sec=health&spn=&pagewanted=all>; Cynthia McFadden & Deborah Apton, *Like Brother, Like Sister? More Teens Getting Controversial Surgery*, ABC NEWS, Nov. 15, 2007, <http://abcnews.go.com/Nightline/DiabetesResource/story?id=3870671&page=1>; Susan Kriemer, *Teens getting Breast Implants for Graduation*, WOMEN'S E-NEWS, June 6, 2004, available at <http://www.womensenews.org/article.cfm/dyn/aid/1861/context/cover/>; Marina Pisano, *Liposuction for Girl, 12, Stirs Debate*, SAN ANTONIO EXPRESS-NEWS, Dec. 5, 2006, available at [http://www.mysanantonio.com/life/MYSA120506\\_1P\\_lipo\\_1e5605b\\_html.html](http://www.mysanantonio.com/life/MYSA120506_1P_lipo_1e5605b_html.html).

<sup>5</sup> Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRIC & ADOLESCENT MED. 1013, 1014 (2006); DAVID R. CARLSON & DEBORAH A. DORFMAN, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" (2007).

<sup>6</sup> Douglas J. Opel & Douglas S. Diekema, *The Case of A.R.: The Ethics of Sibling Donor Bone marrow Transplantation Revisited*, 17 J. OF CLINICAL ETHICS 207 (2006) (describing a case in which a sibling was forced to donate bone marrow to save the life of a brother who sexually abused her).

<sup>7</sup> See *infra* Part III for an explanation about the relative responsibility of parents and physicians in medical decisionmaking for children.

children's body for social, aesthetic, familial, or cultural reasons. I call these shaping cases,<sup>8</sup> and I find them troubling.

In bioethics and law, the traditional academic response to troubling cases involving children is an in-depth analysis of the facts of a particular case or the intricacies of a particular intervention to determine whether the intervention at issue is so harmful or potentially harmful as to justify limiting parental choice.<sup>9</sup> Indeed, I have conducted harm-based analyses on some of the cases mentioned above.<sup>10</sup> The typical analysis weighs the risks of harm versus benefits of the procedure. Much ink is spilled identifying harms and debating their significance.<sup>11</sup> Application of a harm-based analysis is a valuable exercise. It ensures consideration of beneficence and justice as a counterbalance to autonomy in ethical analysis. The debates about harm also broaden our understanding of the physical, moral, and psychological stakes for the children, and fairness and justice implications for society of specific medical interventions.<sup>12</sup> But their starting point is

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<sup>8</sup> The name is borrowed from The Hastings Center, a major bioethics research institute, which coined the term "shaping children" to describe the use surgical interventions designed with the purpose of changing a child's appearance. See ERIC PARENS, *SURGICALLY SHAPING CHILDREN: TECHNOLOGY, ETHICS AND THE PURSUIT OF NORMALITY* (2006). I use the term "shaping cases" slightly differently. Unlike the Hastings Center, which includes surgery to repair a cleft lip or palate as a shaping case because it is used to make children look more normal, I include as shaping cases only those involving the use of surgical or medical intervention that provide no medical, therapeutic, or functional benefit to child. I would argue that surgery for cleft lip or palate restores function to the child's face by allowing the face to perform as intended as a tool of social entry.

<sup>9</sup> See, e.g., Vita Maria Salvemini, *Idiopathic Short Stature or Just Plain Short: Why the Federal Government should regulate the Administration of Human Growth Hormone to Healthy Children*, 38 GA. L. REV. 1105 (2004); Douglas J. Opel & Douglas S. Diekema, *The Case of A.R.: The Ethics of Sibling Donor Bone marrow Transplantation Revisited*, 17 J. OF CLINICAL ETHICS 207 (2006); Samuel J. Tilden, *Ethical and Legal Aspects of Using an Identical Twin as a Skin Transplant Donor for a Severely Burned Minor*, 31 AM. J.L. & MED. 87 (2005); Dov Fox, *Safety, Efficacy, and Authenticity: The Gap Ethics and Law in FDA Decisionmaking*, 2005 MICH. ST. L. REV. 1135 (2004); Therese Powers, *Race for Perfection: Children's Rights and Enhancement Drugs*, 13 J.L. & HEALTH 141 (1999).

<sup>10</sup> See Alicia Ouellette, *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case*, 8 HOUS. J. HEALTH L. AND POL. (forthcoming 2009) [hereinafter *Lessons from the Ashley X Case*]; Alicia Ouellette, *Eyes Wide Open: Surgery to Westernize the Eyes of an Asian Child*, 38 HASTINGS CTR. REP. 15 (2009).

<sup>11</sup> E.g., Christine Ryan, *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 (2008) (discussing the risks and benefits of the "Ashley Treatment"); Nancy Press, *Genetic Testing and Screening*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 73-78 (Mary Crowley ed., 2008) (discussing the benefits and harms of genetic testing); John William McDermott, *Growth Attenuation in the Profoundly Developmentally Disabled: A Therapeutic Option or a Socioeconomic Convenience?*, 32 SETON HALL LEGIS. J. 427 (2008) (describing the harms of parental autonomy in child-rearing decisions that involve invasive medical procedures); Mark S. Frankel & Cristina J. Kapustij, *Enhancing Humans*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 73-78 (Mary Crowley ed., 2008) (providing an analysis of the harms associated with enhancement technologies).

<sup>12</sup> E.g., 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, 56-59 (2000) (analyzing the long-term impact of surgical treatment for intersex children and its impact on the children's right to an open future); Karen Gruney, *Sex and The Surgeon's Knife: The Family Court's Dilemma . . . Informed Consent and the Specter of Iatrogenic Harm to Children With Intersex Characteristics*, 33 AM. J. L. AND MED. 625 (2007) (describing the physical, psychological and social

parental rights, which effectively limits the debate to value judgments about the results of, or benefits gained by a particular intervention.

This Article takes a different tact. Instead of focusing on a single case or intervention, I focus on shaping cases generally. Instead of identifying and weighing the harm or potential harms at stake for children, I ask what shaping cases tell us about the contours of the relationship between parents and children. In other words, I focus not on the ends sought by parents, but on the “human disposition [that shaping of children] expresses and promotes.”<sup>13</sup> I adopt this approach because I believe that the real problem with shaping cases lies in the assertion of parental power involved and the acquiescence of the medical provider to it, and I believe that offering an alternative frame for discourse about medical decisionmaking for children that questions, rather than assumes, parental power may allow health law and bioethics to develop decisionmaking processes that better protect children than does the traditional harm-based framework.

An examination of shaping cases from the perspective of the parent-child relationship reveals that shaping interventions are a product of a “social world that prizes mastery and control,”<sup>14</sup> in which parents may be asserting their will onto their child in a way that disrespects the child as a human being. The law’s support for this exercise of parental power is rooted in an understanding of children’s bodies as a form of property over which the parents have a possessory interest. Such a construct distorts the parent-child relationship and objectifies children. I propose an alternative. Building on models of the parent-child relationship developed in family law and moral philosophy, I suggest a trustee-based construct of the parent-child relationship, in which the parent is given trustee-like powers and responsibilities over a child’s welfare and future interests, and charged with fiduciary-like duties to the child.

Part I of the Article describes cases in which parents exercised their power to shape their children through elective medical and surgical interventions: a case involving a white father who used surgery to reshape the eyes of his adopted Asian child; another in which parents used human growth hormone to add a few inches onto the adult height of their son; a third in which a mother consented to liposuction for her twelve-year-old daughter; and the case of Ashley X, a young girl with profound disabilities whose parents elected to stunt her growth and remove her breasts and uterus in order to continue caring for her at home. Part II sets forth the legal parameters currently governing medical decisionmaking for children. Part III makes the case that the medical or surgical shaping of children is problematic because it objectifies children’s bodies based on a distorted understanding of the parent-child relationship as one in which the parent has possessory rights over a child’s body. Part IV explores from the family law perspective an understanding of an adult’s relationship with children as one of trusteeship, not ownership. Part V argues for a reconstruction of conception of the parent-child

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implications of medical interventions for intersex children); Vita Marie Salvemini, *Idiopathic Short Stature or just Plain Short: Why the Federal Government Should Regulate the Administration of Human Growth Hormone to Healthy Children*, 38 GA. L. REV. 1105, 1107-07 (2004) (exploring the risks of HGH treatment for healthy children).

<sup>13</sup> Michael J. Sandel, *The Case Against Perfection: What’s Wrong with Designer Children, Bionic Athletes, and Genetic Engineering*, in BONNIE STEINBOCK ET AL., *ETHICAL ISSUES IN MODERN MEDICINE* 895 (7th ed. 2009).

<sup>14</sup> *Id.* See also, MICHAEL J. SANDEL, *THE CASE AGAINST PERFECTION: ETHICS IN THE AGE OF GENETIC ENGINEERING* 86 (2007).

relationship in medical decisionmaking for children that adopts from family law and moral philosophy the notion of parent as trustee of the child's welfare and future interests. And Part VI applies the trust-based model of the parent-child relationship to the four focus cases to show that importing a trust-based model of parenting into health law can help distinguish parental choices that belong to the parent from those that should be reserved for the child and those that cannot be entrusted to either parent or child.

### I. Sculpting, Shaping, and Sizing Children: Focus Cases

The use of physical interventions to size and shape children is not new. For centuries parents bound the feet of their young daughters to keep them dainty.<sup>15</sup> With the help of doctors, parents have stunted the growth of tall girls by administering high doses of estrogen,<sup>16</sup> used surgery to “correct” ambiguous genitalia,<sup>17</sup> and lengthened limbs on dwarf children.<sup>18</sup> In some cultures, parents elect to cut the genitals of young girls to conform to cultural norms.<sup>19</sup> This section briefly describes four modern cases in which parents elected to shape, sculpt, and size their children's bodies through elective surgical and medical interventions. Choosing the focus cases for the Article was difficult.<sup>20</sup> The four I discuss, eye shaping, human growth hormone, liposuction, and growth attenuation, represent a good cross section of the shaping work that is currently being done on or to children. The four case studies vary in important ways. They range from the frivolous to the profound. They involve very young and older children, adopted and natural born children, fully capacitated and profoundly disabled children. Each of the distinctions between the cases, from the intrusiveness of the intervention involved to the age of the child, to the child's mental capacity, could arguably make a moral, ethical, or legal difference in an analysis of an individual case.

I want to suggest the opposite — that the similarities between these four very different cases are more important than the differences and that the things that make them similar should make a legal difference. How are these cases the same? These are true shaping cases: the point of the procedures was to modify the child's body for aesthetic, social, or cultural reasons, not to address or correct an underlying illness or physical impairment. They were all products of parental judgments about what is in a child's best

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<sup>15</sup> ELIZABETH HAIKEN, *VENUS ENVY: A HISTORY OF COSMETIC SURGERY* (1997); KATHY DAVIS, *DUBIOUS EQUALITIES & EMBODIED DIFFERENCES: CULTURAL STUDIES ON COSMETIC SURGERY* 93 (Rowman & Littlefield 2003).

<sup>16</sup> HAIKEN *supra* note 16; WILLIAM N. TAYLOR, *HORMONAL MANIPULATION: A NEW ERA OF MONSTROUS ATHLETES* 107-108 (1985).

<sup>17</sup> Alice D. Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 *J. CLINICAL ETHICS* 345, 345-48 (1998). Many first person narratives recounting individual traumas are contained in *INTERSEX IN THE AGE OF ETHICS* (Alice D. Dreger ed., 1999).

<sup>18</sup> *E.g.*, Emily Sullivan Stanford, *My Shoe Size Stayed the Same: Maintaining a Positive Sense of Identity with Achondroplasia and Limb-lengthening Surgeries*, in *PARENS*, *supra* note 9, at 29.

<sup>19</sup> L. Amede Obiora, *Bridges and Barricades: Rethinking Polemics and Intransigence in the Campaign Against Female Circumcision*, 47 *CASE. W. RES. L. REV.* 275, 277 (1997).

<sup>20</sup> Early drafts of the paper included a case involving a parent's decision to make a minor child a skin donor for a sibling. I replaced that case with the human growth hormone case because the physical risks to the child in the HGH case are arguably lower than the risks in the other cases. The skin donation case involved physical risks comparable to liposuction and eye shaping surgery.

interests, but the interventions were in no way therapeutic.<sup>21</sup> They were medically unnecessary, physically invasive, and undeniably risky. They were, by definition, elective, and effected at the parent's request, not on the recommendation of a physician. Another commonality between the cases is that none is reported in case law. My reports about them come from serendipity, medical journals, and the internet.<sup>22</sup>

#### A. Westernizing Asian Eyes

I heard about the first case while attending a presentation at a local hospital. There, a white plastic surgeon, spoke glowingly about surgery he elected for his adopted Asian daughter. She came to his family with eyes that he deemed problematic because, like the eyes of many people of Asian descent, his daughter's eyes lacked a fold in the upper eyelid. As a result, he thought she looked sleepy and he was concerned that her eyes closed completely when she smiled. He proudly reported that he had solved the problem by having his daughter's eyes surgically shaped through a procedure called blepharoplasty. He was thrilled with the results. His beautiful daughter now has big round eyes that stay open and shine even when she smiles. He seemed certain that his decision to use surgery to shape his daughter's eyes will improve her life.<sup>23</sup>

Although blepharoplasty is among the most common procedures performed by plastic surgeons in the United States<sup>24</sup> carries risks. Originally designed "specifically to Westernize the eyelid at the patient's request,"<sup>25</sup> the procedure is done on an outpatient basis. After the patient is sedated and anesthetized, the surgeon makes an incision above the eyelid, removes excessive skin, tissue under the skin, and fat pads.<sup>26</sup> The surgeon then sutures the incision and packs the eye with a light dressing. Once the wound heals, the incision disappears in the newly formed crease. In addition to the usual risks of surgery, eye shaping surgery poses the risk of hematoma, asymmetry, and drooping. Recovery may be uncomfortable. A woman who had the procedure as an adult said that

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<sup>21</sup> Therapeutic interventions are those aimed at preventing or treating disease or injury, or returning functionality to species normal. See ROBERT M. VEATCH, *THE BASICS OF BIOETHICS* 156 (2000); Lisa Fishbayn, "*Not Quite One Gender or the Other*": *Marriage Law and the Containment of Gender Trouble in the United Kingdom*, 15 AM. U. J. GENDER SOC. POL'Y & L. 413, 440 (providing a discussion of procedures that constitute "therapeutic" surgery).

<sup>22</sup> Although I am primarily concerned about whether the power to elect the procedures is one that should rest with parents in the first place, my case descriptions include a brief synopsis of the risks and benefits. The alternatives in all the cases was to do nothing, as none of the features altered was threatening the child's physical health.

<sup>23</sup> I described the same case in a short essay in the Hastings Center Report. Some of the information reported here is copied from that paper.

<sup>24</sup> The American Society of Plastic Surgeons reports that eyelid surgery was performed 241,000 times in 2007. See AMERICAN SOCIETY OF PLASTIC SURGEONS, 2008 REPORT OF THE 2007 STATISTICS, NATIONAL CLEARINGHOUSE OF PLASTIC SURGERY STATISTICS (2008), available at [http://www.plasticsurgery.org/Media/Press\\_Kits/Procedural\\_Statistics.html](http://www.plasticsurgery.org/Media/Press_Kits/Procedural_Statistics.html). Of those, 2,265 procedures involved children between 13 and 19. *Id.* No statistics are kept on the use of cosmetic surgeries on children under the age of 13.

<sup>25</sup> Charles S. Lee, *Blepharoplasty, Asian*, EMEDICINE, Feb. 13, 2008, available at <http://www.emedicine.com/plastic/topic425.htm>.

<sup>26</sup> *Id.*; McCurdy JA, *Upper blepharoplasty in the Asian patient: the 'double eyelid' operation*. 13 FACIAL PLAST. SURG. CLIN. NORTH AM. 47 (2005).

after the operation “she had to sleep in a semi-standing position and ‘when you lay down, it feels like the swelling is burying you.’”<sup>27</sup>

## B. Hormones for Stature

In the summer of 2004, the FDA approved human growth hormone treatments for children who are very short but otherwise healthy.<sup>28</sup> Although the FDA approved the use of HGH in healthy children only when the child’s predicted adult height is four feet, eleven inches for females, and five feet, three inches for males, or 2.25 standard deviations below the mean for the child’s age and sex,<sup>29</sup> the FDA decision does not regulate off-label prescription of HGH to children who do not fall within the FDA guidelines.<sup>30</sup>

As a result, pediatricians today “hear parents ask for GH because their son (and it's usually sons) is as ‘short as I was in grade school,’ or ‘is the shortest one on the team.’”<sup>31</sup> Other parents “are seeking the drug — and no doubt obtaining it — for use in children who are of normal height and even for use in some who are tall, in the hopes that the drug will enable them to grow tall enough to become successful basketball players.”<sup>32</sup> Although some doctors refuse parental requests for HGH for healthy children, others defer to parental choice.<sup>33</sup> Thus a parent with financial means who can find a willing provider can administer HGH to his son to give him a better shot at making the varsity basketball team.

A course of treatment with HGH requires subcutaneous injections three to six times a week over the course of four or five years. The hundreds of injections can be expected to increase a child’s adult height by about one and a half inches.<sup>34</sup> The treatment will not make a short person tall; a child who would have been five feet tall as an adult without the injections, would likely be five feet one and half inches, or five foot two after treatment. And the long term risks of the treatment are not known. It is clear that the treatment may cause musculoskeletal pain, aggression, and aggravation of kidney problems. It poses long term risks of diabetes, hypertension, and cancer.<sup>35</sup>

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<sup>27</sup> Christina Valhouli, *Asian eyes: Some turn to glue or surgery for a new “look”*, SALON MAGAZINE, Feb. 16, 2000, available at [http://archive.salon.com/health/feature/2000/02/16/asian\\_eyes/print.html](http://archive.salon.com/health/feature/2000/02/16/asian_eyes/print.html).

<sup>28</sup> Food and Drug Administration, *FDA Approves Humatrope for Short Stature*, FDA TALK PAPER, July 25, 2003, available at [www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html](http://www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html).

<sup>29</sup> *Id.*

<sup>30</sup> “Off label use” is the use or prescription of a medical device or drug for a use which is legal, but has not received FDA approval. See James E. Beck & Elizabeth D. Azari, *FDA, Off-Label Use and Informed Consent: Debunking Myths and Misconceptions*, 53 FOOD & DRUG L.J. 71, 76 (1998).

<sup>31</sup> Rahulk K. Parikh, *Growth Hormone for Kids, Normal Boys and Girls are Taking Growth Hormone for Being Short. That’s a Bad Prescription*, SALON MAGAZINE, Oct. 31, 2008, available at [http://www.salon.com/env/vital\\_signs/2008/10/31/growth\\_hormones\\_kids/](http://www.salon.com/env/vital_signs/2008/10/31/growth_hormones_kids/) (providing a pediatrician’s view on the use of HGH in healthy kids).

<sup>32</sup> Maxwell J. Mehlman, *How Will We Regulate Genetic Enhancement?*, 34 WAKE FOREST L. REV. 671, 679 (1999) (explaining that obtaining statistics on such off label uses is impossible).

<sup>33</sup> *Id.* See also Vita Marie Salvemini, *Idiopathic Short Stature or just Plain Short: Why the Federal Government Should Regulate the Administration of Human Growth Hormone to Healthy Children*, 38 GA. L. REV. 1105, 1107-07 (2004) (collating statistics about use of HGH in healthy children).

<sup>34</sup> Ellen Werber Leschek et al., *Effect of Growth Hormone Treatment on Adult Height in Peripubertal Children with Idiopathic Short Stature: A Randomized, Double-Blind, Placebo-Controlled Trial*, 89 J. CLIN. ENDOCRINOLOGY & METABOLISM 3140-3148 (2004).

<sup>35</sup> See, Salvemini, *supra* at 1110.

In addition to physical risks, the use of HGH may cause children psychological or psychosocial harm. Although parents and physicians often believe that giving a child an inch or two extra of adult height will increase a child's self esteem and social status, the evidence is to the contrary. Studies show that in the long run, the psychosocial adaptation and self-esteem of treated children is comparable to a placebo group, and that repeated injections increase the child's negative self image and associated stigmatization of height as a defining feature of the child's existence.<sup>36</sup>

### C. Liposuction on a Twelve Year Old

Brooke Bates was 12-years old when her parents persuaded a plastic surgeon to use liposuction to remove 35 pounds of fat and fluid from her body.<sup>37</sup> Brooke and her parents were thrilled with the results, calling it a miracle. But the surgery did not keep Brooke from putting weight back on. When the weight returned in less than a year, the parents returned Brooke to the operating room for a tummy tuck.<sup>38</sup> A year later, her parents brought her to Mexico for lap band surgery after US doctors refused to perform the procedure.<sup>39</sup>

Brooke may be the youngest known person to have been shaped by liposuction, but she is not the only child on whom the procedure has been used.<sup>40</sup> The American Society of Plastic Surgeons reports 4,960 cases of liposuction on patients between the ages of 13 and 19 in 2007. Liposuction is not an effective treatment for obesity in any patient, adult or child.<sup>41</sup> Clinical studies have demonstrated that lipoplasty does not reduce the risk of heart disease, diabetes, or increase metabolism. It is an intervention designed to sculpt contours into a person's body by removing pockets of fat. The surgery itself poses the risk of infection, embolism, puncture wounds in the organs, seroma, nerve compression, changes in sensation, swelling, skin necrosis, burns, fluid imbalance, toxicity, and even death.<sup>42</sup>

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<sup>36</sup> Linda D. Voss, *Is Short Stature a Problem? The Psychological View*, 155 EUR. J. ENDOCRINOLOGY 39 (2006). For a fascinating explanation of how attention to a condition may make a condition stigmatizing and therefore a negative factor in a child's self esteem, see Brenda Major and Laurie T. O'Brien, *The Social Psychology of Stigma*, 56 ANN. REV. PSYCHOLOGY 393 (2005) (explaining, among other things, how stigma is an attribute that discredits an individual "reducing him or her from a whole and usual person to a tainted and discounted one"). For a fascinating account of the lingering psychosocial effects of treatment with HGH of a child with a hormonal deficiency, see David Davis, *Growing Pains*, L.A. WEEKLY, Mar. 21, 1997.

<sup>37</sup> *Too Young for Lipo?*, PEOPLE MAGAZINE, Nov. 3, 2006, available at [http://www.people.com/people/article/0,26334,1554089\\_1,00.html](http://www.people.com/people/article/0,26334,1554089_1,00.html) (explaining that plastic surgeon Robert Ersek only capitulated to the parent's request for surgery after learning that the father was sick with cancer).

<sup>38</sup> *Too Young, Teen Gets Stomach Band After Lipo*, ABCNEWS.COM, Aug. 15, 2007, available at <http://abcnews.go.com/GMA/OnCall/Story?id=3481336&page=1>.

<sup>39</sup> *Id.*

<sup>40</sup> See PLASTIC SURGERY STATISTICS, *supra* note 26.

<sup>41</sup> Denise Grady, *Liposuction Doesn't Offer Health Benefit, Study Finds*, N.Y. TIMES, June 17, 2004, available at [www.nytimes.com](http://www.nytimes.com). Laurie Barclay, *Liposuction Does Not Improve Metabolic Abnormalities Linked to Obesity*, 350 N. ENG. J. MED. 2542 (2004).

<sup>42</sup> Food and Drug Administration, *What are Risks and Complications Associated with Liposuction?*, available at <http://www.fda.gov/cdrh/liposuction/risks.html>.

#### D. Growth Stunting

The case of Ashley X may be the most highly debated of the focus shaping cases. Ashley X was a six-year-old white female who was a patient at the Children's Hospital of the University of Washington in 2004.<sup>43</sup> Ashley had profound developmental disabilities of unknown etiology.<sup>44</sup> For reasons the doctors could not explain, her mental development had never advanced beyond that of an infant.<sup>45</sup>

When Ashley was six years old, her parents began to fear for their daughter's long-term future.<sup>46</sup> Future growth would, the parents feared, make it impossible for them to care for their daughter at home.<sup>47</sup> The parents consulted Ashley's physicians about their options.<sup>48</sup> Her mother suggested a plan for growth attenuation and surgical stunting of Ashley's sexual development.<sup>49</sup> The plan had three main components. The doctors would perform a hysterectomy, a mastectomy,<sup>50</sup> and administer to Ashley high doses of estrogen to stunt her growth permanently.<sup>51</sup> The hysterectomy would prevent Ashley from menstruating; the mastectomy would prevent Ashley from developing mature breast tissue; and the estrogen therapy would prevent Ashley from reaching her projected adult height and weight. The goal of the procedures was to keep Ashley in a child-sized body to allow the parents to continue to take care of Ashley at home. The parents did not want Ashley's care "in the hands of strangers."<sup>52</sup>

The physicians supported the parents' choice, but recognized that the intervention was unprecedented.<sup>53</sup> As a result, they referred the case to the hospital's ethics committee,<sup>54</sup> which met with the family, Ashley, and Ashley's doctors "for over an hour."<sup>55</sup> The Committee considered the potential risks and benefits of each of the three main components of the proposed intervention, and ultimately reached consensus that the

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<sup>43</sup> This description of Ashley's case is an abbreviated version of that in my article *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case*, 8 HOUS. J. HEALTH L. AND POL. (forthcoming 2009). The case was initially made public by Ashley's doctors. See Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRIC & ADOLESCENT MED. 1013, 1014 (2006).

<sup>44</sup> *Lessons from the Ashley X Case*, *supra* note 11.

<sup>45</sup> *Id.*

<sup>46</sup> *Id.*

<sup>47</sup> *Id.*

<sup>48</sup> *Lessons from the Ashley X Case*, *supra* note 11.

<sup>49</sup> *See id.*

<sup>50</sup> The parents refer to this part of the interventions by the more benign sounding "breast bud removal." Parents' Blog, *The "Ashley Treatment," Towards a Better Quality of Life for "Pillow Angels," available at <http://pillowangel.org/Ashley%20Treatment%20v7.pdf>* (last visited Dec. 30, 2007) [hereinafter Parents' Blog]. The Children's Hospital Ethics Committee, however, described the protocol in its ethics opinion regarding this intervention as a "mastectomy." See DAVID R. CARLSON & DEBORAH A. DORFMAN, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 6, 7, 19 (2007) (describing Special CHRCM Ethics Committee Meeting/Consultation (May 4, 2004) and the ethics opinion given by the Children's Hospital Ethics Committee).

<sup>51</sup> CARLSON & DORFMAN, *supra* note 6, at 7.

<sup>52</sup> *Id.*

<sup>53</sup> Gunther & Diekema, *supra* note 6, at 1014.

<sup>54</sup> *Id.*

<sup>55</sup> Special CHRCM Ethics Committee Meeting/Consultation 2 (May 2004), in CARLSON & DORMAN, *supra* note 6, at exhibit L [hereinafter Committee Meeting].

administration of high dose estrogen, hysterectomy, and mastectomy were all ethically appropriate: “It was the consensus of the committee members that the potential long term benefit to Ashley herself outweighed the risks; and the procedures/interventions would improve her quality of life, facilitate home care, and avoid institutionalization in the foreseeable future.”<sup>56</sup> Having identified no reason to interfere with parental authority, the committee left the decision to proceed in the hands of the parents. They consented, and the interventions were implemented without judicial review.<sup>57</sup> The surgeons removed Ashley’s uterus and her breast buds in an “uneventful” surgery.<sup>58</sup> They also removed her appendix,<sup>59</sup> and administered several courses of high dose estrogen.

Each of the interventions performed on Ashley carried physical risks. The potential risks of administration of high dose estrogen included “increased potential for deep vein thrombosis, possible weight gain, possible nausea.”<sup>60</sup> The risks of a hysterectomy include “anesthesia, surgery, and post-operative recovery period, with the additional short term discomfort and suffering.”<sup>61</sup> The physical risks of mastectomy were “minimal” at the time of Ashley’s surgery with the patient’s breast development being rudimentary.”<sup>62</sup>

## II. The Law, Parental Rights, and Children’s Bodies

The focus cases involved the use of medicine, surgery, or genetic modification to modify the body of a child who had no medical need for modification. The interventions all caused the child some kind of physical damage, and they were all entirely optional. That shaping cases are invasive, irreversible, potentially dangerous, and done for reasons other than therapy makes them different from other parental decisions that shape a child.<sup>63</sup> But current law does not reflect that difference. None of the shaping cases described in the previous section went to court. Only one was the arguable subject of any legal regulation.<sup>64</sup> Although shaping cases raise questions about parental rights, parental

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<sup>56</sup> *Id.*

<sup>57</sup> The hospital later admitted that it erred by failing to seek judicial review of the decision to remove Ashley’s uterus. Carol M. Ostrom, *Children’s Hospital Says it Should have Gone to Court in Case of Disabled 6-year-old*, SEATTLE TIMES, May 8, 2007. The physicians were asked specifically about the part of the Committee’s report that noted the need for judicial review of the hysterectomy, but were advised that such review was unnecessary because the procedure was not being performed to sterilize Ashley, but for other purposes.

<sup>58</sup> Gunther & Diekema, *supra* note 6, at 1014.

<sup>59</sup> Parents’ Blog, *supra* note 50 (“The surgeon also performed an appendectomy during the surgery, since there is a chance of 5% of developing appendicitis in the general population, and this additional procedure presented no additional risk. If Ashley’s appendix acts up, she would not be able to communicate the resulting pain. An inflamed appendix could rupture before we would know what was going on, causing significant complication.”).

<sup>60</sup> *Id.*

<sup>61</sup> *Id.*

<sup>62</sup> *Id.*

<sup>63</sup> *See* Part III *infra*.

<sup>64</sup> Washington law arguably required court review of the hysterectomy performed on Ashley. A decision of the Washington Supreme Court requires court review of decisions to sterilize people with developmental disabilities. *In re Hayes*, 608 P.2d 635, 641 (Wash. 1980). There is some debate about the application of that case to Ashley’s case because her parents were not seeking to sterilize Ashley but to decrease the risks of thrombosis caused by the estrogen treatment and to prevent Ashley from becoming upset at the sight of her own menstrual blood, but following the media storm of attention on Ashley’s case,

obligations, and child rights, the law's first concern with respect to medical decisionmaking for children is the protection of parental rights.

### A. Background Law

U.S. law recognizes the right of competent adults to make their own medical decisions.<sup>65</sup> Grounded in constitutional and common law, the right to choose among medical options allows people to refuse treatment, even lifesaving treatment, and to elect treatment, even dangerous cosmetic procedures. Children are obviously not competent adults. While ethicists insist that young children must assent and teenagers consent to medical procedures,<sup>66</sup> the law places decisionmaking for children squarely in the hands of their parents or guardians with very few exceptions. The general rule, applicable in almost all situations,<sup>67</sup> is that a parent is free to sort among alternatives and elect the course of treatment based on his or her assessment of what is in the child's best interests.<sup>68</sup> In other words, parental decisions to use medically unnecessary surgeries for aesthetic or social reasons are treated like parental decisions to attend church or select a school.<sup>69</sup> As a practical matter, the law allows parents with financial means<sup>70</sup> and access to a willing provider to make and implement decisions to size or sculpt their children.

The broad discretion afforded parents in medical cases is rooted in family autonomy. The Supreme Court has recognized the "family as a unit with broad authority over minor children"<sup>71</sup> in which the parents have the authority raise children as parents see fit. The right to familial autonomy allows parents to make most decisions about the care and keeping of children without government oversight or interference.<sup>72</sup> Of course,

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the hospital admitted it should have sought court review of the decision to remove Ashley's uterus. Carol M. Ostrom, *Children's Hospital Says it Should have Gone to Court in Case of Disabled 6-year-old*, SEATTLE TIMES, May 8, 2007, at 1. As I've argued before, however, the need for court review of the hysterectomy in Ashley's case is somewhat beside the point. Such review would not likely have changed the outcome in Ashley's case and will not be required in future growth attenuation cases on boys or those involving only high dose estrogen. See Ouellette, *Ashley*, *supra* note 11 (manuscript at 23–24).

<sup>65</sup> *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) (recognizing the right of a competent adult to make her own health care decisions, but upholding state regulations over decisionmaking for incompetent adults).

<sup>66</sup> See, e.g., Kimberly M. Mutcherson, *Whose Body Is It Anyway? An Updated Model of Healthcare Decision-Making Rights for Adolescents*, 14 CORNELL J.L. & PUB. POL'Y 251, 256–65, 293–98, 303–10 (2005); Andrew Popper, *Averting Malpractice by Information: Informed Consent in the Pediatric Environment*, 47 DEPAUL L. REV. 819, 832 (1998); Lawrence Schlam & Joseph P. Wood, *Informed Consent to the Medical Treatment of Minors: Law and Practice*, 10 HEALTH MATRIX 141, 148–52 (2000).

<sup>67</sup> For a discussion of the exceptions, see text accompanying notes 81–87 *supra*.

<sup>68</sup> See *Parham v. J.R.*, 442 U.S. 584, 602–03 (1979); see also discussion *infra* Part II.C.

<sup>69</sup> *Id.* at 603–04.

<sup>70</sup> Parents pay for elective cosmetic procedures out of pocket. Ashley's health insurer paid for her care. Gunther & Diekema, *supra* note 6, at 15 (citing Parents' Blog, *supra* note 50).

<sup>71</sup> *Parham*, 442 U.S. at 602.

<sup>72</sup> "Choices about marriage, family life, and the upbringing of children are among associational rights [the Supreme] Court has ranked as 'of basic importance in our society,' . . . rights sheltered by the Fourteenth Amendment against the State's unwarranted usurpation, disregard, or disrespect." *M.L.B. v. S.L.J.*, 519 U.S. 102, 116 (1996) (internal citation omitted). Parents therefore have a constitutionally protected liberty interest in the care, custody, and management of their children. See *Santosky v. Kramer*, 455 U.S. 745, 753–54 (1982); *Hurlman v. Rice*, 927 F.2d 74, 79 (2d Cir. 1991); *van Emrick v. Chemung County Dep't of Soc. Servs.*, 911 F.2d 863, 867 (2d Cir. 1990); see also *Stanley v. Illinois*, 405 U.S. 645, 649–52 (1972) ("rights to conceive and . . . raise one's children have been deemed 'essential' and 'basic

parental rights are not unfettered. Although “custody, care, and nurture of the child reside first in the parents,”<sup>73</sup> parental rights are tempered by legitimate rights and interests of their children, and a state’s interest in the health and safety of children. As a result, states may intervene on behalf of abused or neglected children,<sup>74</sup> limit parental authority to send their children to work,<sup>75</sup> and require that children be vaccinated.<sup>76</sup>

In areas of law outside healthcare, children’s rights and children’s voices are taking on increasingly important roles.<sup>77</sup> Indeed, in some areas of family law, children’s rights and welfare trump parental rights.<sup>78</sup> Legal theorists describe a shift in the law’s understanding of the parent-child relationship from a traditional hierarchical model to other models that give varying levels of respect to children as autonomous beings.<sup>79</sup>

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civil rights of man”) (internal citations omitted); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (“the custody, care and nurture of the child reside first [with] the parents”); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (liberty guaranteed by the Fourteenth Amendment includes the right to establish a home and bring up children).

<sup>73</sup> *Prince*, 321 U.S. at 166.

<sup>74</sup> The State has a profound interest in the welfare of the child, particularly his or her being sheltered from abuse. In “emergency’ circumstances,” *Hurlman*, 927 F.2d at 80 (citing *Robison v. Via*, 821 F.2d 913, 921 (2d Cir. 1991)), a child may be taken into custody by a responsible State official without court authorization or parental consent. “Emergency circumstances mean circumstances in which the child is immediately threatened with harm.” *Id.* (citing *Robison*, 821 F.2d at 922). “[T]he mere ‘possibility’ of danger” is not enough. *Id.* at 81. If it were, officers would always be justified in seizing a child without a court order whenever there was suspicion that the child might have been abused. *See id.* The law thus seeks to strike a balance among the rights and interests of parents, children, and the State. *See Hollingsworth v. Hill*, 110 F.3d 733, 739 (10th Cir. 1997); *Robison*, 821 F.2d at 920.

<sup>75</sup> *See, e.g., Wisconsin v. Yoder*, 406 U.S. 205, 226–29 (1972) (holding that while the state had a compelling interest in “universal compulsory education,” Amish children were allowed to quit schooling and begin working after graduating eighth grade because of their parents’ religious belief in preparing for life in the Amish community); *Sturges & Burn Mfg. Co. v. Beauchamp*, 231 U.S. 320, 325–26 (1913) (upholding prohibition against work by children under the age of sixteen in hazardous occupations). “Constitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights.” *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 74 (1976) (citing *Breed v. Jones*, 421 U.S. 519 (1975); *Goss v. Lopez*, 419 U.S. 565 (1975); *Tinker v. Des Moines Indep. Cmty. Sch. Dist.*, 393 U.S. 503 (1969); *In re Gault*, 387 U.S. 1 (1967)).

<sup>76</sup> *See, e.g., Vernonia Sch. Dist. 47J v. Acton*, 515 U.S. 646, 656 (1995) (“[f]or their own good and that of their classmates, public school children are routinely required . . . to be vaccinated against various diseases”); *Zucht v. King*, 260 U.S. 174, 176–77 (1922) (statute mandating compulsory vaccination for schoolchildren was within the state’s police power regulate public health).

<sup>77</sup> *E.g., In re Gault*, 387 U.S. 1, 4 (1967) (requiring juvenile courts to afford children due process rights to counsel, notice, and cross examination); *Goss v. Lopez*, 419 U.S. 565, 584 (1975) (holding that children have a due process right to present their case before being suspended from school).

<sup>78</sup> *See, e.g., In re Appeal in Pima County Juvenile Severance Action No. 5-113432*, 872 p.2d 1240 (Ariz. Ct. App. 1994) (holding that a child may petition to sever parental rights); *Peregoud v. Cosmides*, 663 So.2d 665 (Fla. Dist. Ct. App. 1995) (granting a child standing to challenge adoption by his biological mother); *Planned Parenthood v. Casey*, 505 U.S. 833, 899 (1992) (upholding Pennsylvania statute requiring a pregnant minor seeking an abortion to obtain consent of one parent or guardian, or to seek judicial bypass of consent requirement).

<sup>79</sup> *See, e.g., Janet L. Dolgin, The Fate of Childhood: Legal Models of Children and the Parent-Child Relationship*, 61 ALB. L. REV. 345, 373–78 (1997) (describing three models through which the courts evaluate decision-making within the parent-child relationship: the Traditional Model, where parents are in exclusive control over their children’s decisions; the Transforming-Traditional Model, where there are exceptions to the parents’ exclusive control in certain situations; and the Individualist Model, where children “become free to make their own decisions and bear responsibility for the consequences of their

The traditional hierarchical model of family is firmly ensconced in health law, however. The Supreme Court has made clear that despite the impact on a child's liberty interest, parents "can and must" make medical judgments for children.<sup>80</sup> "Most children, even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment."<sup>81</sup> The child's wishes are essentially irrelevant. "The fact that a child may balk at hospitalization or complain about a parental refusal to provide cosmetic surgery does not diminish the parents' authority to decide what is best for [a] child."<sup>82</sup>

Of course parental discretion over medical treatment is limited in some medical cases. Parents are not free to refuse life-sustaining treatment for a child.<sup>83</sup> Their say over a minor's decision to have an abortion is limited.<sup>84</sup> Some states give children the right to decide about contraception and drug treatment,<sup>85</sup> and others give full decisionmaking power to mature and emancipated minors.<sup>86</sup> Parental rights are also limited with respect to particular medical choices. For example, federal law prohibits genital cutting<sup>87</sup> and limits parental authority to enroll children in experimental protocols,<sup>88</sup> and some states subject parental decisions to sterilize or institutionalize a child to review by a neutral third party or court.<sup>89</sup>

## B. Application in Shaping Cases

The exceptions to the general rule of parent's choice do not apply to shaping cases. The use of shaping interventions does not deprive children of life saving treatments, involve drug treatment, abortion, or institutionalization. Although shaping interventions implicate children's rights to bodily integrity, they do so no more than other cases involving medical and surgical interventions. And in those cases, courts will not even consider the child's best interests unless there is *uniform* medical consensus that a requested intervention is medically inappropriate. In fact, courts routinely reject challenges to parental authority based on the child's best interests when the intervention sought has the support of even one medical provider.<sup>90</sup>

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actions"). See also, Part IV *infra* (discussing the application of alternative models to medical decision-making).

<sup>80</sup> *Parham v. J.R.*, 442 U.S. 584, 603 (1979).

<sup>81</sup> *Id.*

<sup>82</sup> *Id.* at 604.

<sup>83</sup> *E.g.*, *In re Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978) (ordering a child undergo chemotherapy over the parents' objections because the treatment had inconsequential side effects and would save the child from certain death within months).

<sup>84</sup> *E.g.*, *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52 (1976) (finding unconstitutional a state statute that granted parents an absolute veto over a minor child's decision to have an abortion).

<sup>85</sup> *Schlam & Wood*, *supra* note 65, at 165–66.

<sup>86</sup> *Id.* at 165.

<sup>87</sup> 18 U.S.C. § 116 (2006).

<sup>88</sup> 45 C.F.R. §§ 46.401–409 (2007) (requiring Institutional Review Board approval of research protocols involving children and strictly limiting non-therapeutic research protocols that parents may elect for their children).

<sup>89</sup> *E.g.*, WASH. REV. CODE § 11.92.043(5) (2005); see *In re Hayes*, 608 P.2d 635, 641 (Wash. 1980).

<sup>90</sup> *In re Hofbauer*, 393 N.E.2d 1009 (N.Y. 1979) (holding that the court would not interfere with parents' decision to forgo conventional chemotherapy for their eight-year-old son who suffered from

Thus, the extent to which the system of parental choice actually protects a child's best interests is highly dependant on parental and medical judgment. Although many doctors refuse to participate in ethically questionable or potentially harmful interventions, many other doctors defer to patient choice, or, in the case of children, parental choice. They balk only when the requested intervention will not achieve its intended goals or will cause harm disproportionate to the benefit achieved. As one well-known physician ethicist teaches, the real question in medical cases involving children is not identifying which medical alternatives represent the best interests of the child but rather "identifying a harm threshold below which parental decisions will not be tolerated."<sup>91</sup> While courts have found that threshold to be crossed by decisions that directly imperil a child's life, reproductive rights, or physical freedom, courts stay away from interfering with parental judgment about the use of medical and surgical interventions. And while some, even most, physicians would refuse to perform invasive non-therapeutic interventions on children, other physicians are more tolerant of physical risk for social or aesthetic benefit. As a result, a parent who has found a willing medical provider appears to be free to shape his or her child.

The requirement that parents find a willing provider is hardly an obstacle to the exercise of their authority to shape. When pediatricians confront medical problems, they determine the available options by evaluating their medical efficacy and ethical appropriateness. Not so with plastic surgeons. By its very nature, plastic or cosmetic surgery is not concerned with medical efficacy, but with aesthetic or social improvement. The American Academy of Facial Plastic and Reconstructive Surgery code of ethics says only that "[a] member must not perform a surgical operation that is not calculated to improve or benefit the patient."<sup>92</sup> The degree to which cosmetic or social interventions benefit a patient is in the eye of the beholder. The shaping procedures used on all four of the children in the focus cases were calculated by the parents to improve or benefit their children, and providers were willing to provide each intervention. So long as some providers believe that aesthetic, social, or familial improvements justify the use of shaping interventions and make them available to kids, courts are unlikely to interfere with parental choices to use them.

That is not to say that no court would ever find abusive the affirmative use of cosmetic shaping procedure on a child. Imagine, for example, a parent who had been transformed through extreme plastic surgeries into something resembling a lizard.<sup>93</sup> Now

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Hodgkin's disease and treat him with laetrile and a special diet instead because a single provider supported their choice.); *In re Hudson*, 126 P.2d 765 (Wash. 1942) (holding that mother was free to refuse surgery to remove her child's deformed arm despite the recommendation by two physicians that it should be removed for the child's health because both courses of action entailed risk).

<sup>91</sup> Douglas S. Diekema, *Parental refusals of medical treatment: the harm principle as threshold for state intervention*, 25 THEORETICAL MED. & BIOETHICS 243, 244 (2004).

<sup>92</sup> AMERICAN ACADEMY OF FACIAL PLASTIC AND RECONSTRUCTIVE SURGERY, CODE OF ETHICS 8 (2000), [http://www.aafprs.org/Code\\_Of\\_Ethics.pdf](http://www.aafprs.org/Code_Of_Ethics.pdf).

<sup>93</sup> See, e.g., <http://www.thelizardman.com/> (showing picture of man surgically modified to look like a lizard); Unusual Goals: Extreme Plastic Surgery, <http://www.plastic-surgeon-directory.com/extreme-plastic-surgery.html> (describing procedures done to effectuate man's desire to look like a lizard as having five Teflon horns subdermally implanted above each of my eyes to form horned ridges; four of his teeth filed into sharp fangs and his tongue has been bifurcated.) Tongue Splitting Surgery, <http://www.infoplasticsurgery.com/facial/tonguesplitting.html> (advertising a board certified plastic surgeon who provides tongue splitting surgery in a nonjudgmental atmosphere).

imagine that our lizard man had a child, and he wanted his child to look more like him, to be a lizard boy. If the father sought out and found a plastic surgeon to split his child's tongue,<sup>94</sup> his actions would likely be deemed abusive (and the surgeon's a ground for professional discipline) because under all objective standards splitting a person's tongue will jeopardize his health and welfare by interfering with the ability to eat and inflicting a stigmatizing condition. By contrast, hundreds of thousands of people choose to use medicine or surgery to shape their eyes, remove fat from their bodies, or modify their size, and providers find the interventions medically acceptable. Given the near complete deference courts afford medical providers over medical judgments, it is unlikely a court would find the provision of these popular services to be abusive.

### C. Room for Regulation

The broad discretion given parents to shape their children's bodies through medically unnecessary medical and surgical interventions is not constitutionally mandated. The same concerns that justify limitations on parental discretion over involuntary institutionalization and sterilization of minors — the magnitude of the potential harm, the potential conflict of interest on the part of the parents, and the potential for abuse of the interventions — would justify limiting parental authority in shaping cases.

As discussed, parental rights over care and custody of children are not unlimited. They must be balanced against children's rights and states' interests in protecting children. The Supreme Court clarified the delicate balance between parental rights and child rights when it comes to medical decisionmaking for a child in *Parham v. J.R.*<sup>95</sup> Although *Parham* is frequently cited as a strong authority for parental rights, it is actually a case in which the Court found enough risk of error in the parent's judgment about what is in a child's best interests that it held that the constitution *required* procedural protections for the child before a parental decision could be implemented.<sup>96</sup>

In *Parham*, the Court considered a challenge to a Georgia law that allowed parents to institutionalize children with psychiatric illness.<sup>97</sup> The plaintiff was a six-year-old boy whose mother resorted to forced institutionalization after her efforts to manage the child at home failed.<sup>98</sup> A lawsuit was instituted on the child's behalf, alleging that he had a due process right to a full adversarial hearing before his constitutional right to liberty could be restrained.<sup>99</sup> The Court recognized that medical interventions implicate children's liberty interests,<sup>100</sup> but also made it clear that the child's rights are, in most

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<sup>94</sup> Perhaps he found Dr. Lotus, whose provides tongue splitting services "to ensure safety for the public. Unless this procedure is offered by a reputable surgeon, those seeking it may be forced to have it in unclean and unsafe environments." <http://www.infoplasticsurgery.com/facial/tonguesplitting.html>

<sup>95</sup> 442 U.S. 584 (1979).

<sup>96</sup> *Id.* at 606–08.

<sup>97</sup> *Id.* at 584.

<sup>98</sup> *Id.* at 589–90.

<sup>99</sup> *Id.* at 584.

<sup>100</sup> *Id.* at 600–01. "Involuntary medical treatment raises questions of clear constitutional importance." *Sell v. United States*, 539 US 166, 177 (2003). *See Winston v. Lee*, 470 U.S. 753, 759 (1985) ("[a] compelled surgical intrusion into an individual's body . . . implicates expectations of privacy and security" of great magnitude); *see also Riggins v. Nevada*, 504 U.S. 127, 133–34 (1992); *Cruzan v.*

cases, co-extensive with the parents' rights over the child.<sup>101</sup> Thus, the Court said the primary right to make medical decisions rests with the parent, and that parents are entitled a presumption that their decisions are in the best interests of the child.<sup>102</sup> But, the Court also recognized expressly "[t]hat some parents 'may at times be acting against the interests of their children.'" <sup>103</sup>

In the case of forced institutionalization of the child, the Court found good reason to reverse the presumption that parents act in a child's best interests. Concerned with the possibility that parental choices to institutionalize children may be made for the benefit of an overwrought parent, not the best interests of a child, the Court turned to "consideration of what process adequately protects the child's constitutional rights by reducing risk of error without unduly trenching on traditional parental authority ..." The Court concluded 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."<sup>104</sup>

Thus, the Constitution allows states to act to protect children from the decisions of their parents in cases involving medical decisionmaking, especially in cases in which the parent's interests cannot be assumed to be co-extensive with the child's.<sup>105</sup> It does not demand that private decisions to shape a child's body be subjected to third-party review like it does decisions to admit a child to a state institution, but it allows for regulation. Shaping procedures are physically invasive, carry with them significant risk, and may be abused by parents not to benefit the child, but to serve the parent's own interests. As a result, legislatures or regulators could impose restrictions on the use of shaping procedures despite debates about the psychological or social efficacy of shaping procedures. The next section explores whether limitations are a good idea.

### III. What is Really Wrong with Medical and Surgical Shaping of Children?

There is a lot at stake for kids who are subjected to medical or surgical shaping. There is physical harm — children's skin is cut or pierced; their tissue or organs are

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Dir., Mo. Dep't of Health, 497 U.S. 261, 278–79 (1990); *Washington v. Harper*, 494 U.S. 210, 221–22 (1990).

<sup>101</sup> *Parham*, 442 U.S. at 601–02.

<sup>102</sup> *Id.* at 602.

<sup>103</sup> *Id.* (quoting *Bartley v. Kremens*, 402 F. Supp. 1039, 1047–48 (E.D. Pa. 1975), *vacated and remanded*, 431 U.S. 119 (1997)).

<sup>104</sup> *Id.* at 606.

<sup>105</sup> *Id.*; see also WASH. REV. CODE § 11.92.043 (2009) (requiring independent third-party review of parental decisions to sterilize or institutionalize their children); *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972) (parents could consent to kidney transplant from one identical twin to the other where transplant was necessary for survival of one twin, risks were negligible, and parents' motivation had been reviewed by neutral third-parties, including the court); *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979) (court authorized parental consent to kidney transplant from the daughter, a 14-year-old with Down's Syndrome, to the son, suffering from endstage renal disease, because the son would continue to deteriorate without the transplant and the daughter would receive psychological benefits from donation); *In re Hayes*, 608 P.2d 635, 641 (Wash. 1980) (parent did not have authority to consent to sterilization of her minor daughter because sterilization impinged significantly and permanently on fundamental liberty interests of the child, rather the child had to be represented by an independent third-party in an adversarial hearing to establish whether sterilization was appropriate).

removed; they are anesthetized, injected, and infused with hormones. There is physical risk of nerve damage, cancer, diabetes, hypertension, and death, and psychological risk of stigma and injury to identity. And there may be harm to the communities in which the children live, such as the creation of a permanent underclass, and misallocation of precious healthcare resources. In any other context, the interventions would constitute abuse,<sup>106</sup> but the involvement of parents and doctors changes the equation so that the decision to intervene is presumed to be in a child's best interests.<sup>107</sup> Even so, the harm-based analysis traditionally applied in evaluating the appropriateness of particular medical interventions for children — the search for a harm so grievous as to justify overriding parental choice — could well justify the regulation of certain shaping procedures. For example, the physical risks of and stigmatizing effects resulting from daily injections of HGH arguably outweigh any benefits that might follow from having an additional inch or two of height.<sup>108</sup> Justice concerns and moral harms weigh against the growth attenuation interventions used on Ashley.<sup>109</sup> These harms are at least as consequential as those that justify limitations on parental choice to enroll a child in non-therapeutic research protocols or to institutionalize a child.<sup>110</sup>

It is my position, however, that a harm-based analysis is of limited use in shaping cases. First, harm-based analyses are necessarily procedure or case specific. Second, they have little traction in practice, especially when directed at the over- or misuse of

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<sup>106</sup> The U.S. Department of Health and Human Services (HHS) defines abuse as the infliction of "physical injury (ranging from minor bruises to severe fractures or death) as a result of punching, beating, kicking, biting, shaking, throwing, stabbing, choking, hitting (with a hand, stick, strap, or other object), burning, or otherwise harming a child . . ." CHILD WELFARE INFO. GATEWAY, WHAT IS CHILD ABUSE AND NEGLECT? 2 (2008), <http://www.childwelfare.gov/pubs/factsheets/whatiscan.pdf>. HHS regulations further provide that an "injury is considered abuse regardless of whether the caretaker intended to hurt the child." *Id.* Cutting a child's eyelids, injecting drugs hundreds of times, cutting a child's abdomen and removing tissue or organs, all fall within this definition.

<sup>107</sup> "Even though it otherwise meets the definition of abuse, it is permissible to cut a child in the context of a surgical procedure when the intrusion is designed to alleviate the patient's own greater physical harm." Doriane Lambelet Coleman, *The Legal Ethics of Pediatric Research*, 57 DUKE L.J. 517, 553 (2007)

<sup>108</sup> See Dov Fox, *Safety, Efficacy, and Authenticity: The Gap Between Ethics and Law in FDA Decisionmaking*, 2005 MICH. ST. L. REV. 1135, 1144–46, 1153–59, 1193–96 (2005), arguing for regulation on this basis.

<sup>109</sup> See, e.g., William Peace, *Protest from a Bad Cripple: Ashley Unlawfully Sterilized*, COUNTERPUNCH, May 26, 2007, <http://counterpunch.org/peace05262007.html> (asking "[w]hat is next? Amputate the legs of paralyzed people because they are at risk for skin problems and blood clots?"); 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> (disability advocate group stating that "[b]enevolence' and 'good intentions' have often had disastrous consequences for the disability community. Throughout history, 'for their own good' has motivated and justified discrimination against us"); William Peace, *Protest from a Bad Cripple: The Ashley Treatment and the Making of a Pillow Angel*, COUNTERPUNCH, Jan. 18, 2007, <http://www.counterpunch.org/peace01182007.html> ("disabled people are not human — they are profoundly flawed and extreme measures will be taken to transform their bodies").

<sup>110</sup> At stake for children in research protocols are physical and moral harm. See Gwendolyn Johnson, *Grimes v. Kennedy Krieger Inst., Inc.: The Court of Appeals of Maryland Distinguishes Special Relationships That May Arise to the Level of a Contractual Relationship Between Researchers and Non-Therapeutic Research Participants*, 9 U. BALT. J. ENVTL. L. 72, 72–73 (2001); Coleman, *supra* note 2, at 530–45. At stake for children who are institutionalized are confinement and stigma. See *Parham v. J.R.*, 442 U.S. 584, 600–01 (1979).

medical or surgical intervention, as opposed to underuse.<sup>111</sup> And third, and most importantly, harm-based arguments don't get to the root of the problem. They take as a given that absent grievous harm or death, parents have a right to modify a child's body. The assumption of parental rights applies equally to medical or surgical modifications made to improve a child's health as it does to modifications made to satisfy a parent's own aesthetic or social preferences.

The assumption that parents have such broad powers over children's bodies should be questioned.<sup>112</sup> No one other than a parent has the power to use children's bodies for their own purposes, and the notion that a parent has a *right* to alter a child's body is inconsistent with principles deeply embedded in law and moral theory — that people are not property; that people are entitled to respect and dignity; and that no person has a right to exercise complete dominion over the body of another.<sup>113</sup>

#### A. The Nonsubordination Principle as a Limit on Individual Rights

In order to assess the proper scope of parental rights, it is helpful to evaluate the moral and legal status of adult persons generally, and the extent to which the moral status of one person may limit the rights of another. Adults are human persons who have moral status that demands a level of respect, dignity, and freedom from arbitrary treatment. The law respects that moral status by affording individuals rights to self determination,<sup>114</sup> bodily integrity,<sup>115</sup> and freedom from confinement.<sup>116</sup> The right to self determination gives people broad power to direct the course of their own lives by engaging in contracts, employment, marriage, establishing a home, bringing up children, and worshipping God

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<sup>111</sup> Compare *In re Hofbauer*, 393 N.E.2d 1009 (N.Y. 1979) (holding that the court would not interfere with parents' decision to forgo conventional chemotherapy for their eight-year-old son who suffered from Hodgkin's disease and treat him with laetrile and a special diet instead), with *In re Sampson*, 278 N.E.2d 918 (N.Y. 1972) (ordering that a child undergo facial surgery and receive blood transfusions despite the mother's religious objection).

<sup>112</sup> I am by no means the first person to question the traditional understanding of parenthood that underlies the current paradigm for medical decisionmaking for children. See, e.g., Katharine T. Bartlett, *Re-Expressing Parenthood*, 98 YALE L.J. 293, 295–98 (1988) (describing the traditional view of "parenthood as exchange" and describing a new construction of the relationship between parent and child, away from parents' rights toward parents' responsibility for constructing a nurturing relationship with their child); James G. Dwyer, *Parents' Religion and Children's Welfare: Debunking the Doctrine of Parents' Rights*, 82 CAL. L. REV. 1371, 1374 (1994) (arguing that the "proffered justifications for parental rights are . . . unsound" and that the "law confer[s] on parents simply a child-rearing privilege, limited in its scope to actions and decisions not inconsistent with the child's temporal interests").

<sup>113</sup> See Dwyer, *supra* note 7, at 1405 (arguing that "it is illegitimate to construe an individual's rights to include an entitlement to exercise extensive control over another person, or any control over a non-consenting person apart from self-defensive measures").

<sup>114</sup> See, Bd. of Regents v. Roth, 408 U.S. 564, 572 (recognizing that "the liberty . . . guaranteed [by the fourteenth amendment] . . . denotes not merely freedom from bodily restraint but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home and bring up children, to worship God according to the dictates of his own conscience, and generally to enjoy those privileges long recognized . . . as essential to the orderly pursuit of happiness by free men.")

<sup>115</sup> See, e.g., *Planned Parenthood of SE. Pa., v. Casey*, 505 U.S. 833, 849 (1992) ("[T]he Constitution places limits on a State's right to interfere with a person's most basic decisions about family and parenthood . . . as well as bodily integrity . . ." (internal citations omitted)).

<sup>116</sup> See, e.g., *Parham v. J.R.*, 442 U.S. 584, 600 (1979) ("A child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment.").

according to the dictates of own's conscience.<sup>117</sup> But the right to self determination is not so broad as to allow its exercise to deny the moral status and corresponding rights of another person. So while an individual has a constitutionally protected right to self determination, that right is limited by the rights of other persons to bodily integrity, self determination, and freedom from confinement.<sup>118</sup> In other words, a person's right to self determination does not include a right to subordinate the life or body of another person for his own purposes.

Application of this "nonsubordination principle"<sup>119</sup> is clear with adults. The most obvious example, of course, is the Thirteenth Amendment's prohibition against slavery and involuntary servitude,<sup>120</sup> which the courts have interpreted to apply beyond the formal institution of slavery to "control by which the personal service of one man is disposed of or coerced for another's benefit[s] . . . ."<sup>121</sup> The prohibition against slavery and involuntary servitude preserves the respect and dignity of one person at the expense of another's liberty interests. For example, the right to contract is a protected liberty interest,<sup>122</sup> but courts routinely refuse to enforce specific performance of personal service contracts in order to avoid subjugating one person to the will of another.<sup>123</sup>

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<sup>117</sup> See, *Meyer v. Nebraska*, 262 U.S. 300, 399 (stating that liberty includes the "right of the individual to contract to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home and bring up children, to worship God according to the dictates of his own conscience, and generally to enjoy those privileges long recognized . . . as essential to the orderly pursuit of happiness by free men.")

<sup>118</sup> See, e.g., *W. Va. State Bd. Of Ed. V. Barnett*, 319 U.S. 624, 630 (1943)( noting that it is conflicts between the freedoms of one party and "rights asserted by any other individual . . . which most frequently require intervention of the State to determine where the rights of one end and those of another begin").

<sup>119</sup> I am using this term to define the limitations one person's liberty interests place on the exercise of another's. James G. Dwyer uses the term "non-subjection principle" in his article *Parents' Religion and Children's Welfare: Debunking the Doctrine of Parents' Rights*, *supra* note 7, at 1406, to define the same idea. Others refer to nonsubordination theory and an anti-subjugation principle to describe the law's abhorance of castes and a principle which prohibits the systematic subordination of a particular group based on a single trait. See, e.g. Owen Fiss, *Groups and the Equal Protection Clause*, 5 PHIL. & PUB. AFF. 107, 157 (1976); See also LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 1438, 1514 (2d ed. 1988) (referring to an "antisubjugation principle"); Erin E. Goodsell, *Toward Real Workplace Equality: Nonsubordination and Title VII Sex-Stereotyping Jurisprudence*, 23 WIS. J.L. GENDER & SOC'Y 41, 46 (2008) (applying nonsubordination theory to Title VII); Cass R. Sunstein, *The Anticaste Principle*, 92 MICH. L. REV. 2410, 2429 (1994)(arguing against laws that maintain second-class citizenship, or lower-caste status, for blacks or women).

<sup>120</sup> "Neither slavery nor involuntary servitude, except as a punishment for crime whereof the party shall have been duly convicted, shall exist within the United States, or any place subject to their jurisdiction." U.S. CONST. amend. XIII, § 1.

<sup>121</sup> *Bailey v. Alabama*, 219 U.S. 219, 241 (1911).

<sup>122</sup> See, *Bd. Of Regents v. Roth*, 408 U.S. at 572 (acknowledging individual right to contract as liberty interest protected by the fourteenth amendment).

<sup>123</sup> RESTATEMENT (SECOND) OF CONTRACTS § 367 cmt. a (1981) (explaining that: "A court will refuse to grant specific performance of a contract for service or supervision that is personal in nature. The refusal is based in part upon the undesirability of compelling the continuance of personal association after disputes have arisen and confidence and loyalty are gone and, in some instances, of imposing what might seem like involuntary servitude.").

The nonsubordination principle also plays a role in criminal and civil laws that prohibit physical abuse and the offensive touching of another human being.<sup>124</sup> No matter how powerful one person's desire to force another to submit to his will, laws prohibiting abuse and battery limit a person's right of self-determination by preventing him from subjugating another's body for his own purposes.<sup>125</sup>

The principle that one individual's right to self-determination does not entitle that person to dominate another, and its converse, that every individual is entitled to full respect and dignity, is reflected in the modern understanding of the marital relationship. Although women were once denied the rights attendant to their human status, the law's evolving understanding of all persons as complete human beings has resulted in serious limits on the power of husbands to dominate their wives. Husbands can no longer rape their wives with impunity.<sup>126</sup> In the abortion context, the "moral fact that a person belongs to himself and not to others nor to society as a whole,"<sup>127</sup> means that a husband's right to direct his own reproductive destiny cannot extinguish a woman's right to make "choices central to personal dignity and autonomy."<sup>128</sup>

The nonsubordination principle applies even to adults who by virtue of their status of incapacity or incarceration are "naturally suited to governance of another."<sup>129</sup> In *Cruzan*, for example, the Supreme Court denied the parent's claim of right to decide to terminate life-sustaining treatment for their adult daughter, who lacked capacity to make her own decisions as a result of injuries sustained in an accident.<sup>130</sup> It reasoned that the decision whether to live or die is so personal to the individual affected, that the State need not "repose judgment on these matters with anyone but the patient."<sup>131</sup> In other words, a state could reasonably decide that certain decisions are so personal they belong to the individual only, even when the individual to whom they belong lacks capacity to make her own choices. Likewise, the Court has recognized that adults with profound retardation have protected interests in bodily safety and freedom from restraint that limit

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<sup>124</sup> See, e.g., N.Y. PENAL LAW §§ 120.00–12 (2009) (prohibiting assault against another person); N.Y. PENAL LAW § 130.52 (2009) (prohibiting forcible touching of another); CAL. PENAL CODE §§ 242.0–243.10 (2009) (prohibiting various forms of battery); see also *United States v. King*, 840 F.2d 1276, 1280–83 (1988) ("[A] parent's contract allowing a third party to burn, assault or torture his child is void.")

<sup>125</sup> "The Thirteenth Amendment prohibits an individual from selling himself into bondage, and it likewise prohibits a family from selling its child into bondage. The Western legal tradition prohibits contracts consenting in advance to suffer assaults and other criminal wrongs. They are void as against public policy. They do not insulate the wrongdoer from civil and criminal liability. Similarly a parent's contract allowing a third person to burn, assault or torture his child is void." *United States v. King*, 840 F.2d 1276 (6<sup>th</sup> Cir. 1988) (citations omitted).

<sup>126</sup> E.g., *People v. Liberta*, 474 N.E.2d 567, 572–3 (N.Y. 1989) ("Nowhere in the common-law world — or in any modern society — is a woman regarded as chattel or demanded by denial of a separate legal identity and the dignity associated with recognition as a whole human being." (quoting *Trammel v. United States*, 445 U.S. 40, 52 (1980))).

<sup>127</sup> *Thornburgh v. Am. Coll. of Obstetricians & Gynecologists*, 476 U.S. 747, 777 n.5 (1985) (Stevens, J., concurring), *overruled in nonrelevant part by Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1992).

<sup>128</sup> *Casey*, 505 U.S. at 851 (striking down spousal notification rule).

<sup>129</sup> Dwyer, *supra* note 7, at 1416–17.

<sup>130</sup> *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

<sup>131</sup> *Id.* at 286.

actions of their caregivers.<sup>132</sup> And despite the diminished liberty of prisoners, they retain "a significant liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause of the Fourteenth Amendment"<sup>133</sup> that prevents the state from exercising unrestrained dominion over their bodies.

## B. Children as Persons, Parental Rights

Application of the nonsubordination principle to parents and children is complicated by the well-established right of parents to direct the upbringing of children.<sup>134</sup> Parental rights allow parents a degree of control over other persons that would be impermissible in any other relationship. But it would be a moral and legal mistake to assume that the law's recognition of parental rights entitles parents to control the body of a child or to make decisions for the child that belong to the adult the child will become. Parental rights spring not from some ownership interest in a child, but from liberty interests in self determination,<sup>135</sup> an interest consistently limited by the rights and moral status of others. As persons, children are entitled to whatever degree of respect and dignity their vulnerable status allows. "Our law views the child as an individual with the dignity and humanity of other individuals, not as property."<sup>136</sup> Neither the fact of custodial status, nor the biologic relationship of parents to children gives parents a right to use, sacrifice, or invade a child's body for his own purposes, or to make decisions for a child that belong to the adult the child will become.<sup>137</sup>

Even the cases explicitly recognizing parental rights can be understood to apply the nonsubordination principle to limit the scope of parental powers in terms of the child's future and present liberty interests. For example, when the Supreme Court upheld a child labor law against a challenge based in part on parental authority to direct the religious upbringing of a child, it famously explained that "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves."<sup>138</sup> Thus, the Court recognized parental power over the religious upbringing of a child but limited its reach at

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<sup>132</sup> *Youngberg v. Romeo*, 457 U.S. 307 (1982) (finding constitutionally protected rights to reasonably safe confinement conditions and freedom from unreasonable bodily restraints where mentally retarded patient received injuries while involuntarily committed to a state institution).

<sup>133</sup> *Washington v. Harper*, 494 U.S. 210, 221–22, 229 ("The forcible injection of medication into a nonconsenting person's body represents a substantial interference with that person's liberty.").

<sup>134</sup> Parents have the rights "to bring up a child in the way he should go." *Prince v. Mass.*, 321 U.S. 158, 164, 166 (1944) ("It is cardinal . . . that the custody, care, and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder."). The "primary role of parents in the upbringing of their children is . . . established beyond debate as an enduring American tradition." *Wis. v. Yoder*, 406 U.S. 205, 232 (1972). *But see*, *Dwyer*, *supra* note 7 (arguing that the notion of parental rights should be abandoned entirely).

<sup>135</sup> *Doe v. Bolton*, 126 F.R.D. 85 (N.D.Ga., 1989) (liberty in the fourteenth amendment implies "freedom of choice in the basic decisions of one's life respecting . . . upbringing of children).

<sup>136</sup> *U.S. v. King*, 840 F. 2d 1276 (6th Cir. 1988) (citing *Ford v. Ford*, 371 U.S. 187, 193 (1962)).

<sup>137</sup> "Neither religion nor parental consent can save the Salem witch trials of children or the sale of a daughter into prostitution or the Padrone system of child labor or the House of Judah system of child beatings." *U.S. v. King*, 840 F.2d 1276, 1283 (6th Cir. 1988) (holding that parents have no right to commit their children to involuntary servitude).

<sup>138</sup> *Prince v. Mass.*, 321 U.S. 158, 170 (1944).

the point at which assertion of that power would interfere with the ability of the adult the child will become to exercise her own rights in the future. Likewise, the well recognized power of parents to direct their children's education<sup>139</sup> is not so broad as to allow parents to deny children an education altogether.<sup>140</sup> Education, acknowledged the Court, promotes children's future autonomy rights by preparing "individuals to be self-reliant and self-sufficient participants in society,"<sup>141</sup> and compulsory education laws ensure that parents do not deny children the opportunity to become self-sufficient participants in society. And in *Parham*, where the Court emphasized parental rights to make medical choices for children, it limited parental power as a matter of law to ensure against erroneous imposition of unnecessary or improper medical treatment, where there was a risk that exercise of parental power could subordinate the child's interest in freedom from unnecessary medical treatment and confinement to the parent's own interests in restraining a problem child.<sup>142</sup>

The nonsubordination principle is further reflected in laws and decisions that authorize intervention on behalf of neglected or abused children, prevent parents from withholding necessary medical treatment,<sup>143</sup> curtail parental authority to sterilize their children,<sup>144</sup> and limit parental power to "deny children exposure to ideas and experiences they may need later as independent and autonomous adults."<sup>145</sup> These laws all limit parental power at the point at which its exercise would subordinate the child's life or body to the interests of the parent. The principle is most visibly at play in the laws regulating use of children as research subjects and in the few cases in which parental decisions to use one child as an organ or tissue donor for another have reached the courts. Federal law strictly limits parental authority to authorize the use of their children as subjects in non-therapeutic research protocols,<sup>146</sup> regardless of parental desires to inculcate children in a value system prizing altruism, or a desire to profit from their

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<sup>139</sup> *Meyer v. Neb.*, 262 U.S. 390 (1923) (recognizing "the power of parents to control the education of their own"); *Pierce v. Soc'y of Sisters*, 268 U.S. 510 (1925) (recognizing the right of parents to send their school-age children to parochial or private schools).

<sup>140</sup> See *Leebaert v. Harrington*, 332 F.3d 134, 140 (Conn. 2003) (explaining that the scope of a parent's right to direct the education of a child does not include a right to exempt one's child from school requirements).

<sup>141</sup> *Yoder*, 406 U.S. at 221.

<sup>142</sup> *Parham*, 442 U.S. at 606-607 (requiring a "probe of the child's background using all available sources, including but not limited to, parents, schools, and other social agencies. Of course, the reviewer must also include an interview with the child.>").

<sup>143</sup> E.g., *Jehovah's Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968).

<sup>144</sup> See *Conservatorship of Valerie N. v. Valerie N.*, 707 P.2d 760 (Cal. 1985) (denying a parents right to sterilize a child without medical necessity); *Ruby v. Massey*, 452 F.Supp. 361 (D.Conn. 1978) (holding that parents had no authority to veto nor give consent to sterilization of their children).

<sup>145</sup> *Parham*, 442 U.S. at 631 (Brennan, J. concurring and dissenting) (citing *Commonwealth v. Renfrew*, 126 N.E.2d 109 (Mass. 1955); *Meyerkorth v. State*, 115 N.W.2d 585 (Neb. 1962), *appeal dismissed*, 372 U.S. 705 (1963); *In re Weberman*, 100 N.Y.S.2d 60 (Sup.Ct. 1950), *aff'd*, 102 N.Y.S.2d 418, *aff'd*, 302 N.Y. 855, 100 N.E.2d 47, *appeal dismissed*, 342 U.S. 884 (1951)).

<sup>146</sup> 45 C.F.R. pt. 46A (restricting the use of healthy children in research to studies that involve no more than "minimal risk."). See also, *Grimes v. Kennedy Krieger Inst.*, 782 A.2d 807 (Md. 2001) (declaring invalid parental consent given to the use of children in non-therapeutic research protocols involving more than minimal risk); *T.D. v. N.Y. State Office of Mental Health*, 650 N.Y.S.2d 173 (N.Y. 1996) (invalidating state regulations that allowed more than minimal risk on children).

child's bodies. The applicable regulations were enacted to protect children as persons with moral and legal status in the wake of a public ethical debate<sup>147</sup> that began with the revelation that Nazi doctors experimented on children during World War II, and reached a critical point when it was learned that healthy but developmentally disabled children at the Willowbrook School in NY were being fed hepatitis-infected feces as part of a study designed to understand the course of the disease and the possibilities for vaccination.<sup>148</sup> The debate about human experimentation gave rise to the National Commission for Protection of Human Subjects of Biomedical and Behavior Science's Belmont Report,<sup>149</sup> the document that establishes the ethical parameters of experimentation on human subjects, and forms the basis of the federal regulations. The Belmont Report requires that human subjects research reflect respect for persons and special protections for children who are, as members of a vulnerable population, particularly at risk of exploitation.<sup>150</sup>

The nonsubordination principle also explains the willingness of courts to review parental decisions to use one child's body to save the life of another child. Although most such cases are decided without court involvement under the current paradigm of

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<sup>147</sup> For a thorough discussion of the debate and the historical evolution of ethical codes governing human experimentation, see, *BEYOND CONSENT: SEEKING JUSTICE IN RESEARCH* (Jeffrey P. Kahn, Anna C. Mastroianni & Jeremy Sugarman eds., 1998). For discussions focused on children in research, see LAINIE FRIEDMAN ROSS, *CHILDREN IN MEDICAL RESEARCH: ACCESS VERSUS PROTECTION* (2006); Randal Baldwin Clark, *Speed, Safety, and Dignity: Pediatric Pharmaceutical Development in an Age of Optimism*, 9 U. CHI. L. SCH. ROUNDTABLE 1 (2002); Rupali Gandhi, *Research Involving Children: Regulations, Review Boards and Reform*, 8 J. HEALTH CARE L. & POL'Y 264 (2005); Anna Gercas, *The Universal Declaration on Bioethics and Human Rights: Promoting International Discussion on the Morality of Non-Therapeutic Research on Children*, 27 MICH. J. INT'L L. 629 (2006); Clifton R. Gray, *The "Greater Good" ...At What Cost?: How Non-therapeutic Scientific Studies Can Now Create Viable Negligence Claims in Maryland After Grimes v. Kennedy Krieger Institute, Inc.*, 32 U. BALT. L. REV. 73 (2002); William G. Kelly, *Ericka and Myron: Canaries in the Mines*, 13 ALB. L.J. SCI. & TECH. 173 (2002); Loretta M. Kopelman, *Children as Research Subjects: Moral Disputes, Regulatory Guidance, and Recent Court Decisions*, 73 MOUNT SINAI J. MED. 596, 599 (2006); Loretta M. Kopelman, *Minimal Risk as an International Ethical Standard in Research*, 29 J. MED. & PHIL. 351 (2004); Loretta M. Kopelman, *Pediatric Research Regulations Under Legal Scrutiny: Grimes Narrows Their Interpretation*, 30 J.L. MED. & ETHICS 38 (2002); Symposium, *Research with Children: The New Legal and Policy Landscape*, 6 J. HEALTH CARE L. & POL'Y 1 (2002); Jennifer Rosato, *The Ethics of Clinical Trials: A Child's View*, 28 J.L. MED. & ETHICS 362 (2000); Lainie Friedman Ross, *In Defense of the Hopkins Lead Abatement Studies*, 30 J.L. MED. & ETHICS 50 (2002); Efi Rubinstein, *Going Beyond Parents and Institutional Review Boards in Protecting Children Involved in Non-therapeutic Research*, 33 GOLDEN GATE U. L. REV. 251 (2003); David M. Smolin, *Address, Non-therapeutic Research with Children: The Virtues and Vices of Legal Uncertainty*, 33 CUMB. L. REV. 621 (2002); William J. Wenner, *Does the Legal System Provide Adequate Protection for Children in Scientific Experiments? The Unanswered Question of Grimes v. Kennedy Krieger Institute*, 8 U.C. DAVIS J. JUV. L. & POL'Y 243 (2004).

<sup>148</sup> See DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBOROOK WARS*, 263 (1984).

<sup>149</sup> NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, *THE*

*BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH* (1978), available at <http://ohsr.od.nih.gov/guidelines/belmont.html>. See also, WORLD MED. ASS'N, *WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI: ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS* (2004) (originally drafted in 1964), available at <http://www.wma.net/e/policy/pdf/17c.pdf>; 2 Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10, at 181-84 (William S. Hein & Co. 1997), available at <http://ohsr.od.nih.gov/guidelines/nuremberg.html>.

<sup>150</sup> BELMONT REPORT, *supra* note 45 at 4.

parental choice, the occasional case has come to the attention of courts. The courts are willing to become involved, despite the impact of their involvement on parental choice, because the parental choice at issue may well sacrifice the donor child's body to serve the interests of the parents and the recipient child, but not the donor child. The courts confronting these cases have uniformly held that they will abide the parent's choice only if the decision will in fact serve the donor child's best interests by preserving an intimate relationship with the recipient sibling.<sup>151</sup> Courts will not countenance subjugation of the donor child's body for someone else's purposes.

Thus, it is clear that parental rights are not so broad as to allow parents to subordinate the life or body of a child for their own purposes. Understanding exactly how the nonsubordination principle applies within the parent child relationship would require a clear understanding of the moral status and corresponding rights of children, however, because like with adult relationships in which the moral status and corresponding rights of one person limit the right of another to self determination, it is the children's status and rights that define the limitations of parental self-determination. I am not prepared to offer a fully articulated theory of children's moral status and rights, but the Supreme Court has made it clear that neither children's bodies, nor certain choices, are the province of parents. Children have recognized liberty interests in bodily integrity, safety, and freedom from bodily restraint,<sup>152</sup> and "a significant liberty interest in not being confined unnecessarily for medical treatment."<sup>153</sup> They also have exclusive rights to make certain fundamental decisions for themselves, and these rights must be preserved for the adult the child will become. Thus it is clear that nothing about being a parent gives parents the right to violate the personhood of the child, and nothing about the fact of medical involvement changes the child's right to human respect.

### C. Medical and Surgical Shaping of Children is Different

Parents make all kinds of decisions that help shape their children. By exposing kids to music or art, parents help shape children's cultural preferences. By reading to young children or choosing special schools, parents help shape children's intellectual development. By feeding children a steady diet of fast food dinners, or putting them on a regular exercise program, parents help shape their children's bodies. Medical treatment decisions also shape children. Decisions to surgically implant a pin and put a cast on a broken leg, or to give stimulants to a child with ADHD also shape children.

These examples of parental shaping are not legally or morally problematic. In each, the parent is fulfilling a duty to care for or nourish a child. The child needs an education, and so the parent introduces art, music, and books. The child needs to eat, and so the parent supplies food. The child's body needs maintenance, and so the parent

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<sup>151</sup> Michelle Goodwin synthesizes these unpublished decisions in *The Politics of Health Law: My Sister's Keeper? Law, Children, and Compelled Donation*, 29 W.N. ENG. L. REV. 357 (2007). See also, Coleman, *supra* note 2.

<sup>152</sup> *Youngberg v. Romeo*, 457 U.S. 307, 320 (1982) (recognizing rights as belonging to all persons regardless of capacity).

<sup>153</sup> *Parham v. J.R.*, 442 U.S. 584, 600 (1979) ("a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment"). See also, *Washington v. Harper*, 494 U.S. 210, 221-220 (1990) ("recognizing a significant liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause of the Fourteenth Amendment.").

provides an exercise program and healthcare. To be sure, the parents involved exercise discretion in deciding how to meet the child's needs, but their authority to act in the first place derives from their obligations to meet the child's basic needs,<sup>154</sup> and their exercise of discretion does not subordinate the child's life or body for the parent's own purposes.

By contrast, decisions to shape a child's body may have nothing whatever to do with the child's needs. A parent may choose to renovate the child's body for the same reasons he would paint a car or renovate a functioning kitchen. The resulting product will be more aesthetically pleasing, a source of pride, easier to operate. This process of manufacture may have been at play in each of the focus cases. It's quite possible that the adoptive father modified his daughter because he preferred the look of round-eyed girls; that the father injected HGH into his son's body to be able to claim rights to a basketball-playing son; that Brooke Bates's parents had her fat removed because they did not want to see it or it brought them shame; and that Ashley's parents stunted her growth and removed her organs to improve their own lives by creating a child who was, in effect, easier to operate than the one to which they gave birth.

Children are not cars. They are not kitchens. They are not a possession of the parent's to be crafted. Children are persons. Treating children as objects of design, products of will, or instruments of ambition objectifies the children in way that denies their personhood by subordinating their present and future interests for the sake of another. Children are thus objectified when subjected to non-therapeutic medicines and surgeries to meet their parent's needs or desires, because their interests in bodily integrity, safety, freedom from confinement for unnecessary for medical treatment,<sup>155</sup> and right to make fundamental decisions concerning their own identities when the time comes that they can exercise those rights are compromised for the sake of their parent's desires. For this reason, medical and surgical shaping cases are morally and legally problematic.

Philosopher Michael Sandel explains the problem from a similar perspective. He argues that when parenting takes on the role of manufacture "the problem lies in the hubris of the designing parents . . . Even if this disposition did not make parents tyrants to their children, it would disfigure the relation between parent and child."<sup>156</sup> Sandel reflects on the teaching of theologian William May that parenthood, more than any other human relationship teaches an "openness to the unbidden."<sup>157</sup> Mays' construct, says Sandel, "appreciates children as gifts as they come, not as objects of design or products of will or instruments of our ambition."<sup>158</sup> It recognizes that "[p]arental love is not contingent on the talents and attributes a child happens to have," but on acceptance of the person the child is. Accepting the child as a gift, he says, does not "mean that parents must shrink from shaping and directing the development of their child" or "be passive in

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<sup>154</sup> That parents have legal and moral obligations to meet the basic need of children is beyond dispute. Parents have a "high duty to recognize and prepare [their children] for additional obligations." *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925). They have a specific "high duty to recognize symptoms of illness and to seek and follow medical advice." *Parham*, 442 U.S. at 602.

<sup>155</sup> *Parham*, 442 U.S. at 600. *See also*, *Washington v. Harper*, 494 U.S. at 221-220 (1990).

<sup>156</sup> MICHAEL J. SANDEL, *THE CASE AGAINST PERFECTION: WHAT'S WRONG WITH DESIGNER CHILDREN, BIONIC ATHLETES, AND GENETIC ENGINEERING*, IN *ETHICAL ISSUES IN MODERN MEDICINE* 894 (7th ed., Steinbock, et al. eds. 2008).

<sup>157</sup> *Id.*

<sup>158</sup> *Id.*

the face of illness or disease.”<sup>159</sup> To the contrary, Sandel says parents have an “obligation to cultivate their children,” which includes healing and preventing sickness and injury. “Healing sickness or injury does not override a child’s natural capacities but permits them to flourish.”<sup>160</sup>

Sandel, then, would identify the difference between the parent’s role in the case of a broken leg and the father’s role in the eye shaping focus case by what the parental choices say about the relationship of the parent to the child. The parent who consents to surgery and casting on the broken leg is not rejecting the child as she came, or overriding the child’s natural capacities. Instead, that parent is fulfilling an obligation to cultivate and allow her to flourish. The adoptive father who consented to surgery to modify the shape of a child’s eyes has failed to appreciate the child as a gift, and rejected the child’s natural capacity as a complete ethnic person. He wanted a child with round eyes that better matched his family. His decision to impose his will on her was an exercise of hyper-agency and hubris that distorted the parent child relationship.

The fact that the father in the eye surgery focus case was a new adoptive parent makes Sandel’s gift analogy feel particularly apt, and the father’s determination to modify his daughter’s ethnic features particularly egregious. Perhaps because adoption already involves an exchange, the moral obligation of an adoptive parent, especially a parent in a cross cultural or cross racial adoption, to respect the child’s individuality is especially clear. But the fact of adoption changes nothing about the moral or legal status of the child. Every child deserves respect for their individual personhood separate from the interests of the parent. Application of the nonsubordination principle in law helps ensure that respect is afforded.

To be sure, the fact that parents have both a right and “high duty to recognize symptoms of illness and to seek and follow medical advice” complicates that task of applying the nonsubordination principle to define the limits of parental rights in the context of medical decisionmaking. Unlike with adult relationships, the line that defines as unacceptable unilateral decisions by one person that interfere with bodily integrity of another person is not at all clear in the parent-child relationship. For example, a parental decision to consent to surgery to insert a pin into child’s broken leg has an immediate impact on the child’s bodily integrity and liberty interests, but the decision is surely a parent’s decision to make. Sandel’s analysis echoes the distinction apparent but not express at law between parental power to use medical interventions to restore and protect health and function from that used for non-therapeutic purposes. In *Parham*, for example, the Court expressly held that “it is necessary that [a third-party] decisionmaker have the authority to refuse to admit any child who does not satisfy the medical standards for admission.” In other words, the Court limited the parents’ power to make health care decisions for the child to decisions that are medically necessary or otherwise therapeutic. That limitation makes sense if the parent’s right to control a child’s health care is understood as rooted in the parental obligation to meet the child’s needs, not in an ownership right over a child’s body.

Unfortunately, the current paradigm for medical decisionmaking understands the parent child relationship as a hierarchical one in which a parent has a broad right to use medicine or surgery to physically invade a child’s body except in exceptional cases

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<sup>159</sup> *Id.* at 894.

<sup>160</sup> *Id.*

involving grievous harm, death, or obvious conflicts of interest. The hierarchical model of family objectifies children by allowing a parent to impose his will on a child without regard for the child's welfare or the child's right to make autonomous decisions as an adult. It should be replaced in favor of a more nuanced model that respects the child as a vulnerable but complete person.

#### IV. Concerning the Child: Another View of Parenthood

Thus far, I have argued that although parents have constitutionally protected authority to make most medical decisions for their children, they have no *right* to use medicine or surgery to shape their children's bodies. The traditional hierarchical model of the family at play in health law, which starts from an assumption of parental power, does not support such a distinction.<sup>161</sup> The law is not wed to the hierarchical model of family, however.<sup>162</sup>

In fact, there is a clear trend outside health law toward increasing respect for children's rights and dignity that is frankly incompatible with the understanding of children inherent in the hierarchical model of family.<sup>163</sup> Children's rights were strengthened in 1967, when the Supreme Court determined that the Fourteenth Amendment's due process clause applied to children, that children are “‘persons’ under our Constitution,”<sup>164</sup> and that children have rights to freedom of expression.<sup>165</sup> By 1979, in abortion and contraception cases, the Supreme Court recognized that minors have a right to privacy, which is at least as important as parental rights.<sup>166</sup> Thus, the law

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<sup>161</sup> The hierarchical model allows for state intervention only in cases in which the parental choice will cause the child grievous harm or death. Ann MacLean Massie, *The Religion Clauses and Parental Health Care Decision-Making for Children: Suggestions for a New Approach*, 21 HASTINGS CONST. L.Q. 725 (1994) (explaining that parents have both “the freedom and the responsibility” to make health care decisions for children. And while, the parents' perspectives and values, including their religious beliefs, will play a part in the choices they make, the state “has defined the parameters of parental freedom: failure to provide adequate medical care amounts to child abuse or neglect and entitles the state to step in and take over the supervision of a child's medical treatment or to punish parents whose violation of their statutory duty has resulted in harm to a child.”). For reasons I've explained, it is unlikely that any court would deem being a few inches taller, having a little less fat, having rounded eyes, or even being smaller and more transportable, to be grievous harms constituting medical abuse.

<sup>162</sup> Martha Minnow identifies “five legal frameworks for thinking about children” that affect the legal construction of family: “child protection, child liberation, children as potential adults, children in need of traditional authority, and social resource redistribution.” Martha Minnow, *What Ever Happened to Children's Rights*, 80 MINN. L. REV. 267, 268 (1995) (advocating for international human rights for children as a means of respecting children as human beings without displacing or undermining parents.”).

<sup>163</sup> See, Barbara Bennett Woodhouse, “*Out of Children's Needs, Children's Rights:*” *The Child's Voice in Defining the Family*, 8 BYU J. PUB. L. 321 (1993); Minnow, *supra* . The notion that children are persons not property is so firmly rooted in modern family law that some commentators take it as a given. See, e.g., Coleman, *Legal Ethics of Pediatric Research*, *supra*.

<sup>164</sup> *Tinker v. Des Moines Indep. Cmty. Sch. Dist.*, 393 U.S. 503, 511 (1969).

<sup>165</sup> *Id.* at 511 (stating “[s]tudents in school as well as out of school are ‘persons’ under our Constitution. They are possessed of fundamental rights which the state must respect, just as they themselves must respect their obligations to the state.”).

<sup>166</sup> See, *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52, 74 (1976) (stating that “[a]ny independent interest the parent may have in the termination of the minor daughter's pregnancy is no more weighty than the right of privacy of the competent minor mature enough to have become pregnant.”); *Bellotti v. Baird*, 443 U.S. 622, 655-656 (1979) (comparing a minor's privacy interest in obtaining an abortion with parental notification requirements).

recognizes that children are rights-possessing persons, not property or extensions of their parents.

But what it means for children to be individual persons with rights is far from clear because these rights-bearing people are needy and vulnerable, and their familial relationships directly affect their welfare.<sup>167</sup> Moreover, these right-bearing but vulnerable persons are part of a familial unit, which is itself afforded constitutional protections. As a result, the role of parents vis-à-vis their children in law varies by context, and is at times conflicting and paradoxical. John Robertson explains:

Children spring from their parents' loins and are dependent on them for many years, yet they are separate persons with interests and rights that on occasion conflict with the interests of parents. Parents control whether they come into existence, but cannot control their existence once they are here. . . .

. . . The parental bundle of rights over children includes great latitude over where children will live, be educated, and the values they will be taught. At the same time, the child's separate personhood strictly limits this bundle of rights. Parents have rearing rights in children, but they also have duties to provide children with food, shelter, and medical care, and to protect their welfare. They may choose their education within parameters set by the state, but they cannot deny them education altogether. If they neglect those duties or physically abuse children, they lose their rights to rear.<sup>168</sup>

Whatever the nature of children's rights, young children cannot make their own healthcare decisions. Young children are especially vulnerable when they are sick or injured. They need care, but they lack capacity to chart their own course by making reasoned judgments about complex science, individual values, and long term consequences. Parents are best situated to make medical decisions for their children because they, more than anyone else, understand the child as an individual with individual needs, pain tolerance, capacity for confinement, values, and fears.<sup>169</sup> As a matter of constitutional law and good policy, then, parents are presumed to "possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions."<sup>170</sup>

#### A. Alternative Models

In efforts to reconcile the competing needs and rights of children, the rights of parents, and interests of the state in protecting children, several prominent family law and moral theorists have suggested models of the family that appear well suited to medical

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<sup>167</sup> See, John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 480-82 (1996).

<sup>168</sup> *Id.*

<sup>169</sup> See, Jaqueline J. Glover, Trends in Healthcare Decisionmaking, 53 MD. L. REV. 1158 (1994) (addressing how families are suited to make medical decisions for family members because of their capacity to serve as clinical helper, tape recorder, and assessor of patient best interest and because of their status as intimates of the patient).

<sup>170</sup> Parham v. J. R., 442 U.S. 584, 602 (1979). "The unique interdependence between the child and the family justifies the family's participation in treatment related decisions. Within the family unit, there is a strong presumption in favor of the parents as primary decision-makers for their children." Erin A. Nealy, *Medical Decision-Making for Children: A Struggle for Autonomy*, 49 SMU L. REV. 133 (1995).

decisionmaking for children. These robust models respect the child as a vulnerable, yet complete individual within an autonomous family unit in ways the hierarchical model of family do not.

For example, Barbara Bennett Woodhouse proposed a “generist perspective [which] views nurturing of the next generation as the touchstone of the family.”<sup>171</sup> The generist perspective does not simply substitute children for adults as autonomous rights-bearers in an adversarial system. It recognizes “that most children's law involves adults acting on behalf of children” and that “[c]hildren do not start out as autonomous beings; they grow into autonomy.” The Woodhouse model views an adult's relationship with children as one of trusteeship rather than as one of ownership. “Adult ‘rights’ of control and custody yield to the less adversarial notions of obligation to provide nurturing, authority to act on the child's behalf, and standing to participate in collaborative planning to meet the child's needs. A generist perspective involves taming the expression of adult power known as ‘rights talk’ in order to redirect the discussion in terms of meeting children's needs.”<sup>172</sup>

Legal philosopher Joel Feinberg also incorporates a conception of parent as trustee in his work defining a child's right to an open future.<sup>173</sup> His model essentially envisions parents as holders in trust of certain future interests that belong to the child. He explains that rights ordinarily can be divided into four categories. First, there are rights that adults and children have in common, such as a right not to be killed.<sup>174</sup> Second, there are rights which are generally possessed only by children and “childlike” adults, which derive from the child's dependence on others for such basics as food, shelter, and protection.<sup>175</sup> Feinberg calls these dependency rights, and they include the child's right to be fed, nourished and protected. Third, there are rights which can be exercised only by adults such as the free exercise of religion.<sup>176</sup> Finally, Feinberg identifies a category of “rights-in-trust,” rights to be “saved for the child until he is an adult.”<sup>177</sup>

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<sup>171</sup> Barbara Bennett Woodhouse, *Hatching the Egg: A Child-Centered Perspective on Parents' Rights*, 14 CARDOZO L. REV. 1747 (1993).

<sup>172</sup> Barbara Bennett Woodhouse, *Hatching the Egg: A Child-Centered Perspective on Parents' Rights*, 14 CARDOZO L. REV. 1747 (1993); Barbara Bennett Woodhouse, *Out of Children's Needs, Children's Rights: The Child's Voice in Defining the Family*, 8 BYU J. PUB. L. 321 (1994) (Considering parents not as holding rights in their children but as fiduciaries entrusted with their children's care and empowered to care for them) “[P]olicy-makers and judges need to see children not as abstract constructions of innocence detached from their surroundings, but as real people embedded in families and communities. These children have their own deep attachments, experiences, and individual needs that may not conform to the child saver's own values or experience.” *Id.*, at 330.

<sup>173</sup> Joel Feinberg, *The Child's Right to an Open Future*, in WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER 124 (William Aiken & Hugh LaFollette, eds., 1980).

<sup>174</sup> *Id.* at 125. See also, Philip Fetzer & Laurence Houlgate, *Are Juveniles Still "Persons" Under the United States Constitution? A New Theory of Children's Constitutional Rights*, 5 INT'L J. CHILDREN'S RTS. 319 (1997) (emphasizing the difference between having a right, and enjoying it.).

<sup>175</sup> *Id.*

<sup>176</sup> *Id.*

<sup>177</sup> *Id.* at 125-126. Laurence D. Houlgate makes a similar argument in *Three concepts of Children's Constitutional Rights: Reflections in Moral Theory*, 2 U. PA. J. CONST L. 77 (1997).

Rights-in-trust, Feinberg argues, include “anticipatory autonomy rights”<sup>178</sup> which will eventually belong to the child when she becomes a “fully formed self-determining adult.”<sup>179</sup> “An example is the right to choose one’s spouse. Children and teenagers lack the legal and social grounds on which to assert such a right, but clearly the child, when he or she attains adulthood, will have that right. Therefore, the child now has the right not to be irrevocably betrothed to someone.”<sup>180</sup>

According to Feinberg, rights-in-trust can be violated before the child is even in a position to exercise them. “The violating conduct guarantees now that when the child is an autonomous adult, certain key options will already be closed to him. His right while he is still a child is to have these future options kept open until he is a fully formed self-determining adult capable of deciding among them . . . .”<sup>181</sup> “For example, an infant of two months has the right to walk freely down the public sidewalk, even though she is not yet capable of enjoying this right. What then could it mean to say that she has the right to freedom of movement? The answer is that it is a right-in-trust. It is a right to be saved for the child until she gains the ability to walk. One would violate this right now by cutting off her legs, making it physically impossible for her to ever be capable of self-locomotion at some future time.”<sup>182</sup> Parents are morally obligated to protect a child’s rights-in-trust now so that the child can exercise them as an adult. When a parent seeks to violate a right held in trust, Feinberg argues, the state should step in: “Children are not legally capable of defending their own future interest against present infringement by their parents, so that task must be performed for them . . . .”<sup>183</sup>

Elizabeth Scott and Robert Scott take the conception of parent as fiduciary farther and more literally than Woodhouse or Feinberg take their constructions of parent as trustee.<sup>184</sup> They propose a model of the family “premised on a fiduciary framework [that] would entrust parents with the duty to raise their children to adulthood, to provide for their physical and psychological needs, and to perform the services of parenthood with reasonable diligence and “undivided loyalty” toward their children’s interests.”<sup>185</sup> Scott and Scott acknowledge the difficulties of applying fiduciary law to the parent child relationship,<sup>186</sup> but they contend that defining parental power by the imposition of duties

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<sup>178</sup> JOEL FEINBERG, *THE MORAL LIMITS OF THE CRIMINAL LAW: HARM TO OTHERS* 38 (1984) (explaining that a person has an interest in something when he “stands to gain or lose” depending upon the outcome).

<sup>179</sup> Feinberg, *supra* note 12, at 126.

<sup>180</sup> Dena Davis, *The Child’s Right to an Open Future: Yoder and Beyond*, 17 *CAP. L. REV.* 93 (1997).

<sup>181</sup> Feinberg, *supra* note 12, at 126.

<sup>182</sup> Houlgat, *supra* note 13, at 86-87.

<sup>183</sup> Feinberg, *supra* note 12, at 128.

<sup>184</sup> Elizabeth S. Scott & Robert E. Scott, *Parents as Fiduciaries*, 81 *VA. L. REV.* 2401 (1995).

<sup>185</sup> *Id.* at 2420.

<sup>186</sup> It is apparent at the outset, however, that applying a fiduciary framework to the parent-child relationship requires accommodation of some peculiar features that distinguish this relationship from many others in the fiduciary category. Given the extensive scope of the relationship, a prescription that parents must systematically subordinate their personal interest to that of the child when the two are in conflict seems unduly burdensome, and ultimately likely to deter prospective parents from taking on the role. Furthermore, enforcement of such an obligation, although theoretically feasible, would require costly and intrusive state supervision of intact families. This effect seems particularly troublesome given the intimacy of the relationship and the presumed importance of

of care and duty of loyalty analogous to those of other fiduciaries will “encourage parents to approach the tasks of child-rearing with an elevated sense of duty and will detect when parents fail to perform those tasks adequately.”<sup>187</sup> In addition, they argue the fiduciary model rewards the fiduciary role. “The role of trustee, for example, invokes respect in the community, signaling that the individual has assumed an important responsibility, and is trustworthy and morally upright. Community recognition of these attributes carries its own reward, enhancing the nonpecuniary value of the fiduciary role.”<sup>188</sup>

Scott and Scott would apply a “parental judgment rule” to afford parent fiduciaries considerable deference, and relax the blanket rule against self dealing that normally applies to trustees.<sup>189</sup> They explain that as a result their relational model would apply “legally-imposed restrictions to only those decisions that reflect a normative consensus about the welfare of children, parents are left with broad discretion to rear their children according to their own values. Thus, a limited domain for legal regulation promotes the shared objective of encouraging investment in the parental role. At the same time, the law reinforces broadly shared social norms that induce parents to internalize an obligation to attend to their children's welfare.”<sup>190</sup>

The models of family proposed by Woodhouse, Feinberg, Scott and Scott, differ in their specifics, and their specifics are subject to criticisms beyond the scope of this paper.<sup>191</sup> Nonetheless, the three models reflect various applications of a core set of common values that frame an understanding of family that respects children as vulnerable, yet independent human beings.

## B. Common Principles

The Woodhouse, Feinberg, Scott and Scott models of family all have the normative goal of promoting child welfare, not parental autonomy. They each position the parent as a trustee or fiduciary, not owner of the child's person. This construct — parent as trustee — reflects an understanding that children are not chattel. They are persons who hold rights, but lack an immediate capacity to enjoy or exercise some of those rights. The trustee construct also recognizes that children have needs that are unique to them as developing persons, and that those needs give rise to parental responsibilities. For example, parents have the responsibility for meeting children's basic needs for food, education, health care, culture, and nurture, and parents must speak for children when children are not able to speak for themselves. In meeting these

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privacy to optimal family functioning. Moreover, the substantial costs to children of replacing parents and of severing the filial bond inhibits the imposition of a sanction that is used to discipline fiduciaries in other contexts.

Thus, a model scheme for regulating the parent-child relationship must attend to the unique features of this familial bond, and some adaptation of the conventional regulatory mechanisms is required. The usefulness of this approach is not diminished by these constraints, however, so long as policymakers appreciate the goals of regulation and evaluate legal rules as means to the prescribed ends.

*Id.* at 2431.

<sup>187</sup> *Id.* at 2542.

<sup>188</sup> Scott & Scott, *supra* note 23, at 2429.

<sup>189</sup> *Id.* at 2438.

<sup>190</sup> *Id.* at 2446.

<sup>191</sup> For example, I've criticized Feinberg's framework for its portrayal of people with disabilities as cheated of life worth living. See Alicia Ouellette, *Insult to Injury*, HASTINGS L.J. (2009).

obligations, parents must have room to exercise discretion and make judgment calls. But because parental authority is defined in terms of children's needs, it is not appropriate for parents to make decisions for the child that will foreclose children's future interests (their undeveloped rights or rights-in-trust) unless such decisions are necessary to fulfill some immediate need of the child. In other words, under a trustee construct parental rights are defined by their duties to children in a manner consistent with application of the nonsubordination principle in the parent-child context.

It is my position that the same principles should guide medical decisionmaking for children to ensure that children are afforded the dignity and respect reflected in these principles. I propose then, to consider application of a trustee-based construct of family in that context. The first task is to delineate the specific rights and duties of a trustee/ parent.

## **V. Reconstructing the Role of the Parent in Medical Decisionmaking for Children**

This section develops an explicit analogy of parents as trustees by considering application of the laws governing trustees and other fiduciaries in the family context. The trustee-based construct I propose borrows from Woodhouse the notion that parents are best regarded as trustees or stewards of their child's welfare,<sup>192</sup> from Feinberg the notion that what parents hold in trust is not the child him or herself, but the child's welfare and future interests,<sup>193</sup> and from Scott and Scott the notion that parents owe their children specific fiduciary-type responsibilities.<sup>194</sup> The goal is to use an understanding of trust-based relationships to define the scope of parental power in medical decisionmaking for children.

Before setting forth the specifics of the synthesized model I wish to explore, I should explain why I am not advocating wholesale application the Woodhouse, Feinberg, or Scott and Scott models. The short answer is that none of them is detailed enough to address the very narrow and complex problem of defining the limits of parental power in medical decisionmaking for children, which is, of course, necessary to achieve the goal of this Article. The trustee analogy drawn by Woodhouse and Feinberg is "only casually drawn, without any systematic attention to the implications of treating parents as fiduciaries."<sup>195</sup> Like Scott and Scott, I wish to "push the analogy beyond rhetoric"<sup>196</sup> and use the trustee analogy to define roles in a complex relationship. The Scott model is more helpful than that of Woodhouse or Feinberg in its development of fiduciaries duties appropriate to the family context and a corollary to the business judgment rule they call the "parental judgment rule."<sup>197</sup> But their model is so broad and sweeping — the Scott and Scott would regulate all of aspects of the parent-child relationship with monitoring,

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<sup>192</sup> Woodhouse, *Out of Children's Needs*, *supra* at 321.

<sup>193</sup> Feinberg, *supra* at 38.

<sup>194</sup> Scott and Scott, *supra*.

<sup>195</sup> Scott & Scott, *supra* at 2419. Feinberg's rhetoric is especially casual because his goal is to define children's rights, not the relational interest of parents and children.

<sup>196</sup> *Id.*

<sup>197</sup> The parental judgment rule establishes a presumption of a reasonable diligence and good faith in the exercise of parental duties. *Id.* at 2441.

bonding, and sanctioning devices<sup>198</sup> — its usefulness for resolving any particular dilemma is limited.<sup>199</sup> As Scott and Scott acknowledge, the application of conflict of interest and duty of loyalty rules varies depending on nature of the fiduciary relationship, which in the family context may be that of agent, corporate director, guardian, or trustee depending on domain.<sup>200</sup> “Predicting the precise domain of these rules *ex ante* is a problematic exercise,”<sup>201</sup> and they offer little guidance about how to resolve the issue. In this respect, Woodhouse and Feinberg are more helpful. Both make strong arguments about the source of parental power and children’s vulnerability which help define the terms of the “trust” at play in the healthcare domain.

Thus, I follow Scott and Scott’s lead in looking to the law governing trustees and other fiduciaries as a tool for understanding the role of parents when acting as trustees of their child’s welfare and future interests. I am not arguing that the law of trusts should be directly incorporated into health law, however. Trust law relies on constant court oversight, which is not appropriate in medical or family decisionmaking.<sup>202</sup> Moreover, deeming parents to be trustees in a technical sense is incompatible with the vast scope of parental obligations<sup>203</sup> and the nebulous nature of the “property” held by parents for children.<sup>204</sup> But consideration of the well-studied power dynamics between trustees and their beneficiaries sheds light on the power dynamics between parents and their children.

#### A. Powers and Responsibilities of Trustees Generally

A trust is a fiduciary relationship with respect to property subjecting the person who holds legal title to the property, the trustee, to duties to manage the trust property for a person with an interest in the property, the beneficiary. A trustee occupies a position of particular responsibility with a primary duty to act wholly for the benefit of the trust and to administer the trust solely in the interest or for the benefit of the beneficiary.<sup>205</sup> The

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<sup>198</sup>Their framework would regulate everything from the formation of families, to the termination of parental rights. They apply it to regulate intact families, and what they call “broken families.” See, *Id.* at 2442. See also, *id.* at 2457 (discussing the regulation of claims of unmarried fathers).

<sup>199</sup> I am also not persuaded by their application of their model to argue for stringent regulation of what they term “broken families.”

<sup>200</sup> Their model would impose relaxed rules against self dealing in some cases, but not in others. See, *Id.* at 2438.

<sup>201</sup> *Id.*

<sup>202</sup> *Parham v. J.R.*, 442 U.S. 584, 607 (1979). The Court found that “[t]he mode and procedure of medical diagnostic procedures is not the business of judges. What is best for a child is an individual medical decision that must be left to the judgment of the physician in each case.” *Id.* at 608. The Court also rejected the “notion that shortcomings of specialists can always be avoided by shifting the decision from a trained specialist using the traditional tools of medical science to an untrained judge or administrative hearing office after a judicial-type hearing.” *Id.* at 609 (stating that in addition to either a law trained judicial or administrative officer, a staff physician would suffice so long as they are free to evaluate the child’s well being and need for treatment).

<sup>203</sup> “Given the extensive scope of the relationship, a prescription that parents must systematically subordinate their personal interest to that of the child when the two are in conflict seems unduly burdensome.” *Scott and Scott, supra*, at 2431.

<sup>204</sup> A trust is recognized at law only when there is a clearly defined trust property. It would be impossible to define a child’s welfare and future interests as a property

<sup>205</sup> Charles J. Goetz & Robert E. Scott, *Principles of Relational Contracts*, 67 VA. L. REV. 1089, 1126-30 (1981) (summarizing the strict obligations imposed upon fiduciaries for the benefit of principals); Jesse DUKEMINIER & STANLEY M. JOHANSON, *WILLS, TRUSTS, AND ESTATES* 851-51 (4<sup>th</sup> ed.

beneficiary's interest in the property of the trust may be present, future, or contingent, but a valid trust requires a clearly defined trust property.<sup>206</sup>

All trustees have "comprehensive powers to manage the trust property and carry out the terms of the trust,"<sup>207</sup> but those powers must be "exercised, or not exercised, in accordance with the trustee's fiduciary obligations."<sup>208</sup> A trustee has the broad discretionary powers to make ordinary decisions in managing, protecting, and improving the thing held in trust.<sup>209</sup> The discretion of a trustee in administering the trust is not unbounded. In managing real property held in trust, for example, the trustee can properly incur expenses to keep maintain and even improve the trust property "if and as the property's retention and improvement are prudent and suitable to the purposes of the trust,"<sup>210</sup> but "[w]here the terms of a trust direct retention of certain property or forbid the making of improvements or certain types of repairs," the trustee lacks authority to make such improvements absent permission of the court.<sup>211</sup>

All of the trustee's powers are subject to fundamental duties of prudence, loyalty, and impartiality.<sup>212</sup> The trustee's primary duty is one of loyalty to the beneficiary. The duty of loyalty requires the trustee to administer the trust solely in the interest of the beneficiary.<sup>213</sup> The trustee violates his duty to the beneficiary when he uses the trust property for his own purposes. Accordingly, the trustee must not engage in transactions that involve the trust property or create a conflict between his duty to the beneficiary and his personal interests.<sup>214</sup> In exceptional circumstances a court may approve a transaction that would be prohibited as self dealing or as involving a conflict of interest if the court determines that "the transaction is in the interest of the beneficiaries,"<sup>215</sup> but the general rule against self-dealing is normally strictly enforced. In some cases, appointment of a trustee ad-litem is appropriate for resolving issues about which the trustee may have a conflict.<sup>216</sup>

The trustee's duty of prudence requires the exercise of reasonable skill, care, and caution in the administration of the trust.<sup>217</sup> "The duty to act with caution does not, of course, mean the avoidance of all risk, but refers to a degree of caution that is reasonably appropriate or suitable to the particular trust, its purposes and circumstances, the beneficiaries' interests, and the trustee's plan for administering the trust and achieving its objectives."<sup>218</sup> When investing assets of the trust, the duty of prudence requires the trustee to act "in the context of the trust portfolio and as a part of an overall investment

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1990)(describing prohibition against self-dealing which is implicated any time the trustee bargains with himself in an individual capacity).

<sup>206</sup> Uniform Trust Code § 103(c).

<sup>207</sup> RESTATEMENT (THIRD) OF TRUSTS § 70(a).

<sup>208</sup> *Id.*, comment a.

<sup>209</sup> "The trustee has a duty to administer the trust, diligently and in good faith, in accordance with the terms of the trust and applicable law." RESTATEMENT (THIRD) OF TRUSTS § 76.

<sup>210</sup> RESTATEMENT (THIRD) OF TRUSTS § 88, comment C.

<sup>211</sup> *Id.*

<sup>212</sup> RESTATEMENT (THIRD) OF TRUSTS § 78.

<sup>213</sup> RESTATEMENT (THIRD) OF TRUSTS § 78.

<sup>214</sup> *Id.*

<sup>215</sup> *Id.*, at comment A.

<sup>216</sup> *Id.*

<sup>217</sup> RESTATEMENT (THIRD) OF TRUSTS § 77 (2).

<sup>218</sup> *Id.*, at comment b.

strategy, which should incorporate risk and return objectives reasonably suitable to the trust.”<sup>219</sup>

A trustee commits a breach of trust by violating a duty as a result of negligence, misconduct, or “mistake concerning the nature or extent of the trustee’s powers and duties under the terms of the trust or applicable law.”<sup>220</sup> For this reason, when there is reasonable doubt about the scope of a trustee’s powers, a trustee or beneficiary may apply to an appropriate court for instructions regarding the administration or distribution of the trust.<sup>221</sup> Resort to the courts is not always appropriate, however. “If a matter rests within the sound discretion of the trustee, or is a matter of business judgment, the court ordinarily will not instruct the trustee how to exercise that discretion or judgment.”<sup>222</sup> Thus, a trustee’s power to exercise his discretion over the trusteeship is afforded presumptive deference and remains beyond review except to the extent that its exercise is inconsistent with his duties to the beneficiary. Those trustee decisions that may constitute an abuse of trust — such as those that suggest self-dealing or that involve a conflict of interest — should not be implemented unless reviewed and deemed appropriate by the court or a trustee-ad litem.

#### B. Powers and Responsibilities of Parent Trustees as Concerns Children’s Health

If a parent is a trustee of the child’s welfare and future interests, then the parent’s powers and responsibilities should parallel those of other trustees as outlined above. This section begins the task of sorting out parental rights and responsibilities in tandem with trust law in an effort to clarify what it means to position the parent as a trustee in the context of healthcare decisionmaking for children. This discussion does not purport, or even attempt, to resolve every medical case involving children. It is useful, however, in identifying those parental decisions to which healthcare providers need not, or should not acquiesce.

The first task in extending the analogy of parent as trustee is to clarify what constitutes the trust “property” held by the parent-trustee, and the terms of the trust under which parents operate. Here, Woodhouse and Feinberg are helpful in their identification of the present and future interests held for the child by the parent trustee, and the parent’s role with respect to those interests. In explaining what it means for a parent to serve as trustee of the child’s welfare, Woodhouse defines parental power in terms of the child’s needs because parental authority is justified not by some ownership right, but by the “limitations childhood imposes on personhood.”<sup>223</sup> Because of his childhood — his uniquely vulnerable state — the child needs from his parent nurturing, safety, health, food, education, culture, and shelter. Feinberg calls these the child’s dependency rights. These basic needs comprise the children’s welfare, which is the “property” held by the parent in trust for the child. The child has both present and future interests in her welfare. As Feinberg explains, the child has future interest in exercising autonomy rights once she

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<sup>219</sup> RESTATEMENT (THIRD) OF TRUSTS § 227(a).

<sup>220</sup> *Id.*, comment A.

<sup>221</sup> RESTATEMENT (THIRD) OF TRUSTS § 71.

<sup>222</sup> RESTATEMENT (THIRD) OF TRUSTS § 71, comment c.

<sup>223</sup> *Dolgin, supra* at 392 (explaining that the Supreme Court in *Parham* “justified the scope of parental authority through reference to the limitations childhood poses on personhood.”)

becomes an adult. Parents hold those rights in trust for the child, and have a duty to preserve them for the child to exercise as an adult.

Implicit in Woodhouse and Feinberg's models is a trust that provides parents express power to protect, nourish, and preserve the child's welfare, but denies them authority to limit a child's future ability to make her own autonomous choices unless the limitation on the child's future interest is necessary to preserve the child's welfare now. In other words, the trust limits the parent's power to foreclose opportunities and choices for the child by imposing on parents an express duty to preserve for the child the ability to make his or her own choices in the future.

Stretching the analogy further to apply principles of trust law clarifies that as trustees, parents have comprehensive powers to manage the trust by making ordinary decisions to protect and preserve the child's health, which is a component of the child's welfare. In fact, most decisions made by the parent trustees to protect and preserve a child's health would be considered discretionary decisions beyond review. Where, for example, a specific physical or psychological need in a child triggers the need for a decision to prevent deterioration of the trust asset (the child's health or a function necessary to becoming an autonomous adult), the parent's decision about how to preserve and protect the child's welfare would be the parent's prerogative so long as it does not violate a fiduciary duty owed the child. The parent's discretionary powers would also include the power to "improve" the child's health through the administration of vaccines, despite the cost injections incur to the child's body, because "retention and improvement [of the child's health, a component of the trust property] are prudent and suitable to the purposes of the trust."<sup>224</sup>

On the other hand, the terms of the trust might be interpreted to limit parental power to make major "improvements" to the child's health. The trust requires parents to preserve for the child the ability to make his or her own autonomous choices in the future. Thus, improving the child at the expense of the child's ability to make future choices or exercise liberty interests as an adult would likely be prohibited absent permission of the court.<sup>225</sup> The exact scope of this limitation is subject to debate, and would need further development if a trustee-based model were implemented. But I would suggest that a parental decision to elect a preventive mastectomy or hysterectomy for a child carrying genes for breast or uterine cancer would be considered an "improvement" beyond the ordinary powers of the parent. Such an improvement would prevent the child from exercising choices about reproduction and bodily integrity as an adult, and as such would likely fall outside the trustee's discretionary authority absent an immediate health crisis in the child triggering a need to act now to preserve the child's physical welfare.

Fundamental duties of prudence, loyalty, and impartiality would limit the power of the parent trustee in the exercise of healthcare decisionmaking for children.<sup>226</sup> In managing the child's welfare and protecting her future interests, the parent's primary duty would be one of loyalty to the child.<sup>227</sup> The parent would violate her duty to the child by using the trust property — the child's welfare and future interests — for her own

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<sup>224</sup> RESTATEMENT (THIRD) OF TRUSTS § 88, comment C.

<sup>225</sup> *Id.*

<sup>226</sup> RESTATEMENT (THIRD) OF TRUSTS § 78.

<sup>227</sup> RESTATEMENT (THIRD) OF TRUSTS § 78.

purposes. Accordingly, the parent would lack the power to make transactions involving the child's health and future autonomy to satisfy the parent's own aesthetic, cultural, or social preferences.<sup>228</sup> In exceptional circumstances a court could approve a transaction that would be otherwise prohibited as self dealing or as involving a conflict of interest, but only after the court determined that the transaction is in the interest of the child.

The duty of prudence would require the parent to exercise reasonable skill, care, and caution in managing the child's welfare.<sup>229</sup> The parent could make some decisions that put the child's health at risk, but would be expected to exercise a "degree of caution that is reasonably appropriate or suitable" to preserving, protecting, and enhancing the child's welfare and future interests."<sup>230</sup> When investing assets of the trust, that is, when risking the health or safety of the child, or limiting the child's ability to make future choices, the duty of prudence would require that parents act "in the context of the trust portfolio and as a part of an overall investment strategy, which should incorporate risk and return objectives reasonably suitable to the trust."<sup>231</sup> In other words, a parent's decisions to risk a child's health or safety would be measured in terms of its overall benefit to the child's welfare and the maintenance of future options.

If treated as a formal trustee, a parent could turn to a court when in doubt about the scope of his or her powers, but courts would not be available to instruct parents as to how to act on matters within their discretion or parental judgment.<sup>232</sup> Even a formal trustee's power to exercise his discretion over the trusteeship is afforded presumptive deference and remains beyond review except to the extent that its exercise is inconsistent with his duties to the beneficiary. Only those decisions that constitute an abuse of trust — such as those that suggest self-dealing or that involve a conflict of interest — would require review by a court or a trustee-ad litem before implementation.

As Scott and Scott recognized, "the unique features of th[e] familial bond" require adaptation of agency theory and trust law.<sup>233</sup> They argue in favor of "a parental judgment rule," a corollary to the business judgment rule applicable to corporate directors, which would afford "parents a presumption of good faith and reasonable diligence in assessing parental performance."<sup>234</sup> Although the business judgment rule does not normally apply to trustees, who are held to the highest duty of loyalty as among all fiduciaries, such a rule might be required for parents under current Supreme Court precedent holding that parental decisions are entitled to presumptive deference.<sup>235</sup>

In applying trust law to the parent-child relationship, I would suggest that it is necessary to appoint a third-party decisionmaker other than a court to resolve conflicts, especially with respect to medical decisionmaking. As the Court recognized in *Parham*, medical professionals are far better equipped than untrained judges to make medical judgments.<sup>236</sup> The emergence of institutional review boards as bodies with authority to

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<sup>228</sup> *Id.*

<sup>229</sup> RESTATEMENT (THIRD) OF TRUSTS § 77 (2).

<sup>230</sup> *Id.* at comment b.

<sup>231</sup> RESTATEMENT (THIRD) OF TRUSTS § 227(a).

<sup>232</sup> RESTATEMENT (THIRD) OF TRUSTS § 71, comment c.

<sup>233</sup> *Scott & Scott, supra* at 2430.

<sup>234</sup> *Id.*, at 2438.

<sup>235</sup> *Parham, Troxel.*

<sup>236</sup> *Parham v. J.R.*, 442 U.S. at 607-608.

oversee the protection of human research subjects suggests the possibility for an expert body for resolving disputes.

Regardless of these specifics, application of trust law to flesh out the role of parent as trustee reveals clearly that parental power to make medical choices for children is not unbounded. The duties of loyalty and prudence restrict the parent's power to use medicine or surgery on a child's body to serve the parent's social, cultural, or aesthetic preferences. Such decisions raise the specter of self-dealing and create a conflict between the parent's duty to the child and the parent's personal interests. In such cases, the responsibility for evaluating such decisions should fall to a neutral third party, the physician, an ethics committee, or a court; but unless someone other than the parent finds convincing evidence that the proposed intervention will address an immediate need of the individual child, the intervention should be put off until the child can make her own decision.

## **VI. Shaping Reconstructed**

Having thus defined the scope of parent's duties and responsibilities by incorporating principles from trust law, it becomes possible to identify a principled approach to medical decisionmaking for children in general and shaping cases in particular that respects children as human beings. As a practical matter, the application of a trustee-based construct to medical decisionmaking for children would change little in the provision of health care to children. Most cases would remain a matter of parental choice. The framework shift would call into question only the rare case in which the parental choice conflicts, or could conflict, with the parent's trustee-like obligations to the child. In those cases, the law would not allow modification of a child's body simply because a parent demands it. Instead, the decision would be subject to third-party review before it could be implemented.

Under the trustee-based construct, all of the focus shaping cases would trigger some kind of third party review, but the outcome of that review would not necessarily be uniform. The outcome would depend on assessment of whether the sought after interventions would protect the child's welfare and future interests. Let us consider each case in turn.

Under a trustee-based construct, the adoptive father's decision to elect eye shaping surgery for his daughter would trigger the need for third party review because it raises the specter of self dealing and creates a conflict between the parent's duty to child and the parent's personal interests. It is unlikely that a parent of a young child could show that the sought-after surgery, which is quite controversial even for adults, would advance the child's present interests to such an extent that it could justify curtailment of the child's ability to make her own decision about surgery and possession of her ethnic trait as an adult. For that reason, it is unlikely that a parent would be allowed to elect ethnic eye shaping surgery for a child under a trustee-based construct.

By contrast, a decision of the parent to use human growth hormone on a child might well be approved by a neutral third party depending on the particular case. Like the eye shaping case, the parental decision would raise the specter of self dealing and a conflict of interest, and therefore trigger the need for someone other than a parent to review the decision before it was implemented. Unlike a decision about eye shaping, however, which could be preserved for the adult the child will become, a decision to use

HGH for height must be made when the child is still too young to make a decision for him or herself. A third party reviewing a request to use HGH would need to determine whether such decision was one that would benefit the child, a hard case to make given the evidence of physical harm and psychological injury generally associated with the treatment. Nonetheless, in rare cases, it might be shown that a particular child's expected adult height will be so short as to cause the child lost opportunities, such as reaching the gas pedal on a car or the ability to reach counters. It might also be shown that a particular child is already suffering from stigma associated with small stature and that the particular child's psychological needs would be served by the treatment. A trustee-based construct makes room for intervention under those circumstances.

Brooke Bate's parents appear to have overstepped their roles as trustees and violated their fiduciary duties when they chose to use liposuction to shape her twelve year old body. The surgical removal of 35 pounds of fat from a twelve year old girl likely violated the parent's duty of prudence because it put the child's health and life at risk for a short lived aesthetic gain. The risks were not offset by any long term physical or psychological gain, suggesting an absence of caution reasonably appropriate or suitable to preserving, protecting, and enhancing the child's welfare and future interests.<sup>237</sup>

As trustees of her welfare and future interests, Ashley's parents would not have had discretionary authority to modify her body in the way they did. The modifications would clearly fall under the category of "major improvements," which were outside the terms of the trust and required third party approval. The request for the interventions would also have raised the specter of self dealing, as the parents may have been trading Ashley's bodily integrity for their own gain. Having said that, however, the reality of caring for a person with profound disabilities in a society that fails to support caregivers and to modify itself to accommodate the needs of persons with disabilities and their families, is so complex that a neutral third party could reach the same conclusion reached by Ashley's physicians and the ethics committee, that her interests would be best served by the modifications despite their costs.

## VII. Conclusion

Allowing parents on demand access to shaping interventions permits parents a degree of control over their children's bodies that is inconsistent with an understanding of the child as an individual person in an autonomous family. A trustee-based construct has several benefits over the current paradigm. Most importantly, it places the child's welfare and future interests at the center. It recognizes the vulnerability of children and the need for someone to make decisions for them. It also respects the autonomy of the family unit by giving parents vast discretion over ordinary parenting decisions. It is, in this way, entirely consistent with the nonsubordination principle because it respects parental authority to act for children when they are limited in their abilities because of their status, but limits parental rights at the point at which their exercise would deny the personhood and corresponding rights of children.

Application of a trustee-based construct does not require wholesale adoption of the heavy handed regulation central to the law of trusts. Rather, the framework speaks to the relational interests between parents and children in a way that makes room for

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<sup>237</sup> *Id.*, at comment b.

nuanced discourse by physicians, ethicists, and lawmakers about the limitations of parental power over children's bodies. When applied, the trustee-based construct continues to allow parents vast discretion over decisions concerning the management of their children's health. Like that of other trustees, however, that power is limited by duties of loyalty and prudence, which invalidate parental choices that may serve the parent's interest at a cost to the child. In such cases, a neutral third party should review the decision and decide whether it is one that can be reserved for the child once she reaches maturity. If the decision can be reserved, it should be. If not, then the third party should approve the use of the intervention only if convinced it will advance the interests of the child. If a proposed intervention will advance only the parent's interests or will unduly foreclose options for the child in the future, it should be denied. Not every decision about a child's body is a parent's to make.