

GROWTH ATTENUATION, PARENTAL CHOICE, AND THE RIGHTS OF DISABLED CHILDREN:

LESSONS FROM THE ASHLEY X CASE

Alicia R. Ouellette, J.D.¹

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¹ Associate Professor, Albany Law School; Professor of Bioethics, Union Graduate College/Mt. Sinai School of Medicine Program in Bioethics. Many thanks to Jerald Sharum, Henrik Weston, and Daniel Wood for their able research assistance on this paper.

I. INTRODUCTION

Most medical cases involving parental choice on behalf of a child proceed with no public oversight. Parental choice is, by design, a private matter. A parent makes medical decisions for a child behind the closed doors of the family doctor or pediatrician's office after evaluating the risks, benefits, and alternatives of a proposed course of treatment. The choices are generally implemented without note in the media or in law. Only the exceptional parental choice, such as a decision to forgo potentially life-saving treatment for a child, may be deemed so risky to the child's future well-being that it triggers court intervention.² Other parental choices, such as those to use elective cosmetic surgery on children, occasionally generate media attention,³ but those decisions are not legally regulated. With few exceptions, the general rule is that unless a particular decision can be characterized as medical neglect, parental decisions about children's health care are subject to virtually no attention or legal limitation.⁴

The case of Ashley X, a profoundly disabled child from Washington whose growth and sexual development were purposely stunted through medical and surgical treatments elected by her parents, is an exception to the normal rule. Not only did Ashley's case generate a storm of media attention,⁵ it is one of the rare cases in

² See Walter Wadlington, *Medical Decision Making for and by Children: Tensions Between Parent, State, and Child*, 1994 U. ILL. L. REV. 311, 318, 320, 325, 331 (discussing cases that allowed court intervention for life-threatening situations).

³ See, e.g., Victoria Clayton, *Way to Go, Grad! Here's a Check for a New Nose: Is Cosmetic Surgery an Appropriate Commencement Gift for Teens?*, MSNBC.COM, May 11, 2007, <http://www.msnbc.msn.com/id/17932515/wid/11915773>; 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&spon=&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>.

⁴ See Part II below for a discussion of the limitations the law does place on parental decisionmaking.

⁵ E.g., Nancy Gibbs, *Pillow Angel Ethics*, TIME, Jan. 22, 2007, available at <http://www.time.com/time/magazine/article/0,9171,1576833,00.html>; Elizabeth Cohen, *Disability Community Decries 'Ashley Treatment'*, CNN.com, Jan. 12, 2007,

which some form of judicial review was arguably required (although it was not sought).⁶ The case and the prospect that other parents of disabled children will seek similar intervention without even a minimal requirement for judicial or other review raise important questions about the law's role in protecting children from the decisions of their parents, and about the rights of disabled children.

This paper argues that the law failed Ashley. It allowed her parents to alter her body profoundly and permanently for social, not medical, reasons without adequate process or oversight. The lack of process was unacceptable given the magnitude of potential harm to Ashley, the potential conflict of interest faced by her parents, and the potential for abuse of the proposed interventions. This paper does not argue that the outcome in Ashley's case would *necessarily* have changed had proper limitations and review been in place. Instead, it identifies the ways in which the limited process afforded Ashley left unexplored the impact of her parents' choice on her rights and the procedures that must be implemented to protect children adequately in cases such as Ashley's in which a parent seeks profound and permanent modifications of a disabled child's body as a means of managing that child's disabilities.

Section II of this paper presents Ashley's case. Section III examines the reaction to Ashley's case by the disability rights community and its demand for a moratorium on similar interventions. Section IV places Ashley's case in the context of other medical-legal cases that have defined the constitutional rights of parents to make decisions for their children and the limitations imposed on parental deference. Section V explores the rights of children implicated in cases like Ashley's, identifies how the lack of process in Ashley's case allowed her rights to go unprotected, and argues that the ethics committee's review of Ashley's case was

<http://www.cnn.com/2007/HEALTH/01/11/ashley.outcry/>; Arthur Caplan, *Is 'Peter Pan' Treatment a Moral Choice?*, MSNBC.com, Jan. 5, 2007, <http://www.msnbc.msn.com/id/16472931/>. On their blog, her parents report that "This story topped the Health section of Google News between January 5th and January 8th [2007] - there have been more than 600 related articles worldwide." Ashley's Mom and Dad, *The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels,"* <http://ashleytreatment.spaces.live.com/> (last visited June 19, 2008) [hereinafter Parents' Blog].

⁶ See 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; see also discussion in text accompanying notes 120-29, *infra*.

deficient. It then sets forth a process that would appropriately protect children for whom interventions like those used to modify Ashley are sought. The paper concludes that the process agreed upon in the settlement between Washington Protection and Advocacy System and the hospital where Ashley was a patient is ethically appropriate and constitutionally sound in any case in which parents seek the "Ashley Treatment."⁷

II. GROWTH ATTENUATION AS MEDICAL "MANAGEMENT" OF DISABILITY: THE CASE OF ASHLEY X

Ashley X was a six-year-old white female patient at the Children's Hospital of the University of Washington in 2004.⁸ Ashley had profound developmental disabilities of unknown etiology.⁹ For reasons the doctors could not explain, her mental development had never advanced beyond that of an infant.¹⁰ Her doctors described her condition at the time the case presented as follows:

At the age of 6 years, she cannot sit up, ambulate, or use language. She is gastrostomy-tube dependent for nutrition . . . [S]he clearly responds to others—vocalizing and smiling in response to care and affection. The combined opinion of the specialists involved in her care is that there will be no significant future improvement in her cognitive or neurologic baseline.¹¹

Ashley's college-educated parents cared for their daughter at

⁷ Ashley's parents coined the term "Ashley Treatment" to describe the collection of procedures used to stunt Ashley's growth and stop her sexual development. The term is a misnomer. Treatment is "[a] broad term covering all the steps taken to effect a cure of an injury or disease . . . including examination and diagnosis." *Black's Law Dictionary* 1346 (5th ed. 1979); see also *Succession of Cormier*, 80 So. 2d 571, 573 (La. Ct. App. 1955); *Lloyd v. County Elec. Co.*, 599 S.W.2d 57, 61 (Mo. Ct. App. 1980); *Witty v. Fortunoff*, 669 A.2d 244, 246 (N.J. 1996); *Little v. Little*, 576 S.W.2d 493, 495 (Tex. Civ. App. 1979). Ashley's growth was not an injury or disease. The medical intervention she received allowed her parents to manage her disabilities, but they did not effect a cure of any medical condition.

⁸ 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).

⁹ *Id.*

¹⁰ *Id.*

¹¹ *Id.*

home where doctors described Ashley as an “integral, and much loved, member of the family.”¹² Her parents called Ashley their “pillow angel” because “she is so sweet and stays right where we place her—usually on a pillow.”¹³ They also described what Ashley’s presence at home means to them:

Ashley brings a lot of love to our family and is a bonding factor in our relationship; we can’t imagine life without her. She has a sweet demeanor and often smiles and expresses delight when we visit with her, we think she recognizes us but can’t be sure. She has a younger healthy sister and brother. . . . As often as we can we give her position changes and back rubs, sweet talk her, move her to social and engaging places, and manage her entertainment setting (music or TV). In return she inspires abundant love in our hearts, so effortlessly; she is such a blessing in our life!¹⁴

Like many children with profound disabilities, Ashley showed signs of early puberty.¹⁵ At age six, she had begun to develop pubic hair and breast buds.¹⁶ Her parents were concerned about the onset of puberty.¹⁷ The doctors noted that “it was clear that the onset of puberty had awakened parental fears for their daughter’s long-term future.”¹⁸ Future growth would, the parents feared, make it impossible for them to care for their daughter at home.¹⁹ Ashley’s parents wanted her to stay at home. They did not want her care “in the hands of strangers.”²⁰

The parents consulted Ashley’s physicians about their options.²¹ Together, they developed a plan for growth attenuation and surgical stunting of Ashley’s sexual development.²² The plan had three main components: the doctors would perform a hysterectomy, a

¹² *Id.*

¹³ Parents’ Blog, *supra* note 5.

¹⁴ *Id.*

¹⁵ Gunther & Diekema, *supra* note 8, at 1014.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ Gunther & Diekema, *supra* note 8, at 1014.

²¹ *Id.*

²² *See id.*

mastectomy,²³ and administer to Ashley high doses of estrogen to stunt her growth permanently.²⁴ 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.²⁵ 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.²⁶

Ashley's parents explained:

Ashley will be a lot more physically comfortable free of menstrual cramps, free of the discomfort associated with large and fully-developed breasts, and with a smaller, lighter body that is better suited to constant lying down and is easier to be moved around.

Ashley's smaller and lighter size makes it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, touch, snuggles, etc. Typically, when awake, babies are in the same room as other family members, the sights and sounds of family life engaging the baby's attention, entertaining the baby. Likewise, Ashley has all of a baby's needs, including being entertained and engaged, and she calms at the sounds of family voices. Furthermore, given Ashley's mental age, a nine and a half year old body is more appropriate and provides her more dignity and integrity than a fully grown female body.²⁷

The physicians supported the parents' choice, but recognized that the intervention was unprecedented.²⁸ As a result, they referred

²³ The parents refer to this part of the interventions by the more benign sounding "breast bud removal." Parents' Blog, *supra* note 5; The "Ashley Treatment," *Towards a Better Quality of Life for "Pillow Angels,"* <http://pillowangel.org/Ashley%20Treatment%20v7.pdf> (last visited Dec. 30, 2007). 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, DISABILITY RIGHTS WASHINGTON, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 6, 7, 19 (2007) (describing Special CHRMC Ethics Committee Meeting/Consultation (May 4, 2004) and the ethics opinion given by the Children's Hospital Ethics Committee).

²⁴ CARLSON & DORFMAN, *supra* note 23, at 7.

²⁵ *Id.*

²⁶ Gunther & Diekeman, *supra* note 8, at 1014.

²⁷ Parents' Blog, *supra* note 5.

²⁸ Gunther & Diekema, *supra* note 8, at 1014.

the case to the hospital's ethics committee.²⁹ The hospital ethics committee at Children's Hospital (hereinafter "Committee") is made up of health care providers from across disciplines, community members with training in medical ethics, and one of the hospital's attorneys.³⁰ It issues "non-binding recommendations to practitioners and family members looking for guidance regarding procedures or practices that appear to raise ethical concerns."³¹ The Committee met with Ashley, her family, and her doctors "for over an hour."³² The Committee's written report notes that the discussion of risks and benefits of the proposed interventions was "thorough, painful and occurred with considerable initial division of the members as to whether or not to support the proposal."³³

The Committee considered the potential risks and benefits of each of the three main components of the proposed intervention. As to the administration of high-dose estrogen, it identified the potential risks as "increased potential for deep vein thrombosis, possible weight gain, [and] possible nausea."³⁴ The Committee identified the potential benefits of growth attenuation as facilitating Ashley's care "by a smaller rather than a larger size, i.e. moving in/out of bed, wheelchair, car, bathtub, and changing position to avoid pressure sores, etc."³⁵ The Committee noted a concern that "this intervention is not a standard of care and would in all likelihood be 'new territory' in the management of profoundly retarded juvenile patients."³⁶

The Committee identified the risks of a hysterectomy as "anesthesia, surgery, and post-operative recovery period, with the additional short term discomfort and suffering."³⁷ The potential benefits included avoidance "of the menstrual cycle, physical

²⁹ *Id.*

³⁰ Mission Statement for the Ethics Committee of the Children's Hospital & Regional Medical Center, in CARLSON & DOREFMAN, *supra* note 23, at Exhibit H.

³¹ CARLSON & DOREFMAN, *supra* note 23, at 13.

³² Special CHRMC Ethics Committee Meeting/Consultation 2 (May 2004), in CARLSON & DOREFMAN, *supra* note 23, at exhibit L [hereinafter Committee Meeting].

³³ Committee Meeting, *supra* note 32, at 3.

³⁴ *Id.* at 2.

³⁵ *Id.*

³⁶ *Id.*

³⁷ *Id.*

discomfort, hygienic issues, confusion and anxiety in an individual unable to understand what is going on.”³⁸ An additional benefit of the surgery, said the Committee, “would be to totally exclude the possibility of the patient being sexually assaulted and impregnated.”³⁹ The Committee noted that Washington law required court review of the hysterectomy.⁴⁰

As to the mastectomy, the Committee identified the potential risk as “minimal at this time with the patient’s breast development being rudimentary.”⁴¹ The potential benefits of removing Ashley’s breast tissue were “comfort/quality of life improvement; there is a family history of large breasts with fibrous cystic disease and breast cancer.”⁴² The Committee also noted that “the restraint strap that holds Ashley in the wheel chair goes right across the area of her body where the breasts would be if they develop,” and a concern that this part of the proposal “is clearly not the standard of care for a minor patient with developmental delay and would, like the limitation of linear growth, be ‘new territory’ in the management of such a patient.”⁴³

After deliberating privately, the Committee reached consensus that the 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.”⁴⁴

Having received the blessing of the Committee, the treatment was implemented without judicial or further review.⁴⁵ The surgeons

³⁸ *Id.*

³⁹ Committee Meeting, *supra* note 32, at 2-3. This conclusion appears to be poorly worded. Obviously, a hysterectomy would do nothing to totally exclude the possibility of a person being sexually assaulted.

⁴⁰ *Id.* at 3.

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ *Id.*

⁴⁵ 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*

removed Ashley's uterus and her breast buds in an "uneventful" surgery.⁴⁶ They also removed her appendix.⁴⁷ They then began a course of high-dose hormones administered through patches placed on Ashley's skin.⁴⁸ The treatment continued for more than a year and was terminated when Ashley's growth was permanently halted.⁴⁹ She reached a final height of four feet, five inches, and a weight of seventy-five pounds.⁵⁰ On their internet blog, Ashley's parents reported that the "Ashley treatment," the hormones, hysterectomy, and mastectomy, cost about thirty thousand dollars, and that all costs were covered by insurance.⁵¹

Ashley's physicians, Doctors Daniel Gunther and Douglas Diekema, published a paper on the case that received widespread media attention.⁵² In their paper, Gunther and Diekema hailed the intervention as "a new approach to an old dilemma," and "a therapeutic option available to [profoundly disabled] children should their parents request it."⁵³ Interestingly, the paper discussed the physicians' use of the estrogen therapy and the hysterectomy, but it did not report on or explain the removal of Ashley's breast buds or her appendix.⁵⁴

Gunther and Diekema considered the ethical issues raised by the

Court in Case of Disabled 6-year-old, SEATTLE TIMES, May 8, 2007. The physicians involved asked specifically about the part of the Committee's report that noted the need for judicial review of that part of the proposed interventions, but were advised that such review was unnecessary because the procedure was not being performed to sterilize Ashley but for other purposes. See *infra* notes 102-105 and accompanying text.

⁴⁶ Gunther & Diekema, *supra* note 8, at 1014.

⁴⁷ Parents' Blog, *supra* note 5 ("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.").

⁴⁸ See Gunther & Diekema, *supra* note 8, at 1014.

⁴⁹ *Id.*

⁵⁰ Elizabeth Cohen, *Disability Community Decries 'Ashley Treatment'*, CNN.COM, Jan. 12, 2007, <http://www.cnn.com/2007/HEALTH/01/11/ashley.outcry>.

⁵¹ CARLSON & DORFMAN, *supra* note 23, at 15 (citing Parents' Blog, *supra* note 5).

⁵² Gunther & Diekema, *supra* note 8.

⁵³ *Id.* at 1013.

⁵⁴ *Id.* at 1014.

interventions.⁵⁵ In particular they considered whether growth attenuation and hysterectomy offered benefits and did any harm to the patient.⁵⁶ Their discussion tracks the report of the Committee, but it also evaluates some alternatives to the proposed interventions. For example, Gunther and Diekema discussed the possibility of using oral medication or injections to control menses as an alternative to surgical removal of the uterus, but concluded that “in these profoundly impaired children, with no realistic reproductive aspirations,” hysterectomy has the advantage of sparing “the individual and her caregivers the expense, pain, and inconvenience of a lifetime of hormone injections.”⁵⁷ In addition, hysterectomy eliminates the need to give progesterone during administration of high-dose estrogen for growth attenuation, which decreases the risk of thrombosis.⁵⁸

In a media interview, Doctor Diekema further explained why he agreed the procedures were in Ashley’s best interests:

When you look at the growth attenuation, the primary benefits are by being a smaller girl, it will be easier for people to lift her, and will allow her to receive a more personal level of care from her parents for a longer period of time. They really want to be able to pick up their daughter and give her a hug and put her in a chair. It will be easier for them to move her to the car and go on outings rather than thinking about leaving her behind with a caretaker when they go on vacation. As far as removing her uterus with a hysterectomy, there are many profoundly disabled children who are traumatized by menstruation. They don’t understand why there is blood coming from that part of their body, and it’s impossible to make them understand. Unlike a normal 11- or 12-year-old, you can’t explain to them this is a normal part of your development. The family wanted to spare Ashley that drama. Ashley’s a little girl who already had experienced being terrified of blood.⁵⁹

Following publication of the doctors’ paper, the parents published a blog on which they celebrated the “Ashley treatment”

⁵⁵ *Id.*

⁵⁶ *Id.* at 1014–16.

⁵⁷ *Id.* at 1015.

⁵⁸ *Id.* at 1015–16.

⁵⁹ Amy Burkholder, *Ethicist in Ashley Case Answers Questions*, CNN.COM, Jan. 11, 2007, <http://www.cnn.com/2007/HEALTH/01/11/ashley.ethicist/index.html>.

and the doctors who helped Ashley by performing it.⁶⁰ In it, they repeated much of the discussion from the Gunther paper. They also elaborated on their decision to remove Ashley's breasts, something the Gunther paper did not address:

Ashley has no need for developed breasts since she will not breast feed and their presence would only be a source of discomfort to her. This is especially true since Ashley is likely destined to have large breasts, given her maternal and paternal female lineage. [For example, an] aunt had a breast reduction operation at age 19.⁶¹

Moreover, they claim, "[l]arge breasts could 'sexualize' Ashley towards her caregiver, especially when they are touched while she is being moved or handled, inviting the possibility of abuse."⁶²

The blog and paper generated considerable controversy and media attention.⁶³ Of particular note is the number of people who posted on the blog indicating that they, too, plan to seek similar management of their child's disabilities.⁶⁴

III. THE AFTERMATH — THE RESPONSE OF THE DISABILITY COMMUNITY TO ASHLEY'S CASE

The publication of Ashley's case and her parents' blog triggered a national debate. The most vocal opponents to the interventions used on Ashley were members of the disability rights groups.⁶⁵ The reaction of these groups was predictable given the poor track record of the medical establishment in dealing with people with disabilities. Past practices such as involuntary sterilization, lifelong institutionalization, and experimentation on people with disabilities were so abusive that many people in the disability rights community are frankly distrustful of medical management of disability.⁶⁶ As

⁶⁰ *Id.*

⁶¹ Parents' Blog, *supra* note 5.

⁶² *Id.*

⁶³ *See generally id.* (posting excerpts and links to various media articles regarding their case).

⁶⁴ *See id.* (posting several of the "thousands of private emails that were sent to PillowAngel@hotmail.com").

⁶⁵ *E.g.*, Cohen, *supra* note 5.

⁶⁶ For a more extended discussion of the disability perspective on the medical establishment

stated by one disability advocacy group, "'[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."⁶⁷ It is not surprising, then, that news of Ashley's case triggered bitter accusations, alarm, and protests by members of the disability rights community.

Some disability activists criticized the motivations of Ashley's parents.⁶⁸ For example, a spokesperson from the disability rights group Not Dead Yet said, "This is an issue of basically subjecting a child to drastic physical alterations to fit the convenience of her caregivers."⁶⁹ Steven Taylor, director of Syracuse University's Center on Human Policy stated, "It is unethical and unacceptable to perform intrusive and invasive medical procedures on a person or child with a disability simply to make the person easier to care for."⁷⁰

Others argued that the management of Ashley's disabilities through growth attenuation and surgery denied her basic rights in a way that dehumanized her and others like her.⁷¹ For example, one advocate wrote:

This is the denial of a child's basic right as a human being to be free from the unwarranted and unnecessary manipulation of [her] basic biological functions merely to satisfy the needs of a third party . . . Children with severe developmental disabilities are, first and foremost, human beings. The manipulation of a child's physical development relegates those receiving such treatment to a less than human category.⁷²

see James A. Charleton, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* (1998); *HANDBOOK OF DISABILITY STUDIES* 351-514 (Gary L. Albrecht et al. eds., 2001) (documenting the experience of disability); Mary Johnson, *MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE, AND THE CASE AGAINST DISABILITY RIGHTS* (2003); Harriet McBryde Johnson, *TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE* (2005); Joseph P. Shapiro, *NO PITY* 12-40 (1993) (classifying the treatment received by people with disabilities as either "Tiny Tims" or "Super Crips").

⁶⁷ Dave Reynolds, *Advocates Speak Out and Call For Investigations Over "Ashley Treatment,"* INCLUSION DAILY EXPRESS (Jan. 12, 2007) available at <http://www.inclusiondaily.com/archives/07/01/12/011207waashleyx.htm>.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ *Id.*

⁷² *Id.* (quoting a letter to the editors of the Archives of Pediatrics and Adolescent Medicine by

Another lashed out, “The message is very clear: disabled people are not human—they are profoundly flawed and extreme measures will be taken to transform their bodies.”⁷³

Some activists questioned the efficacy and safety of the procedures. The procedures do not ensure that Ashley would be cared for at home, they said, “because the future development of any six-year-old child will depend on many factors, [and as a result,] the medical, social and programmatic needs of the adult Ashley will become cannot be anticipated with certainty.”⁷⁴ Others noted the unknown risks of the use of estrogen in the profoundly disabled.⁷⁵

Other activists argued that the case is a dangerous precedent that could be used to justify additional invasive elective procedures on people with disabilities. “What is next?” asked a blogger, “Amputate the legs of paralyzed people because they are at risk for skin problems and blood clots?”⁷⁶ In a similar response, a disability rights position paper argues that under the rationale used to support the modification of Ashley:

[If] weight ever becomes a difficulty due to age-associated loss of strength for the parents (rather than obesity of the child), then . . . bariatric surgery or severe restriction in caloric intake would be a form of therapy. If that proves insufficient, the goal of reducing the size of the child could be addressed by “amputation-therapy,” justified by the fact that the patient would never be ambulatory in any event.⁷⁷

Based on these arguments, disability rights groups across the country called for a moratorium on growth attenuation and surgery

TASH board president Lyle Romer).

⁷³ William Peace, *The Ashley Treatment and the Making of a Pillow Angel*, COUNTERPUNCH (Jan. 18, 2007) available at <http://www.counterpunch.org/peace01182007.html> (discussing the ethics and social aspects of mutilating disabled people).

⁷⁴ Position Statement, Bd. of Directors of the Am. Assoc. on Intellectual & Developmental Disabilities, *Unjustifiable Non-therapy: A Response to Gunther & Diekema (2006) and to the Issue of Growth Attenuation For Young People on the Basis of Disability* (n.d.), http://www.aamr.org/Policies/board_positions/growth.shtml (last visited Oct. 19, 2008) [hereinafter AAIDD Board Position Statement].

⁷⁵ *Id.*; Jeffrey P. Brosco & Chris Feudtner, *Growth Attenuation: A Diminutive Solution to a Daunting Problem*, 160 ARCHIVES PEDIATRIC & ADOLESCENT MED. 1077, 1077-78 (2006).

⁷⁶ William Peace, *Protest from a Bad Cripple – Ashley Unlawfully Sterilized*, COUNTERPUNCH, May 26, 2007, available at <http://counterpunch.org/peace05262007.html>.

⁷⁷ AAIDD Board Position Statement, *supra* note 74.

in children with disabilities.⁷⁸ A statement from the American Association in Intellectual and Developmental Disabilities represents the views of the groups:

It seems painfully obvious that medical practice for an individual can rapidly degenerate if the anxieties of the parents regarding as yet unclear future issues replace the medical best interest of the child as the primary focus, even with the noblest of intentions of all parties involved. . . . [W]e believe that this practice, if judged acceptable, will open a doorway leading to great tragedy. This door is better left closed.⁷⁹

At the same time disability activists and groups were reacting to Ashley's case, the Washington Protection and Advocacy System (WPAS), a federally-mandated watchdog agency with authority to investigate allegations of abuse and neglect of persons with disabilities in Washington, initiated an investigation of "what happened to Ashley."⁸⁰ Its report concluded the hysterectomy violated Ashley's constitutional and common law rights because it was conducted without a court order as required under Washington law.⁸¹ The report further concluded that surgical breast bud removal and hormone treatment "should require independent court evaluation and sanction before being performed on any person with a developmental disability."⁸²

WPAS also negotiated a plan for the future with Children's Hospital. In light of the WPAS report, Children's Hospital conceded error in failing to seek a court order before allowing its doctors to

⁷⁸ See, e.g., *id.*; *Chicago Area Advocacy Groups Meet with AMA to Voice Opposition to "Ashley's Treatment"* CATALYST (Coalition of Citizens with Disabilities in Illinois, Springfield, Ill.), (Mar. 2007), available at http://www.ccdionline.org/newsletter.php?article_id=32& (reporting that Feminist Response In Disability Activism, Not Dead Yet, and Chicago ADAPT had demanded a moratorium on the performance of future "Ashley Treatments"); F.R.I.D.A., Feminist Response In Disability Activism, <http://fridanow.blogspot.com/search?q=Ashley%27s+Treatment> (search "Search Blog" for "Ashley's Treatment") (listing articles relating to FRIDA's position on "Ashley Treatments"); Not Dead Yet, <http://notdeadyetnewscommentary.blogspot.com/search?q=Ashley%27s+Treatment> (search "Search Blog" for "Ashley's Treatment") (last visited Oct. 18, 2008) (listing articles relating to FRIDA's position on "Ashley Treatments").

⁷⁹ AAIDD Board Position Statement, *supra* note 74.

⁸⁰ CARLSON & DORFMAN, *supra* note 23, at 1.

⁸¹ *Id.* at 27.

⁸² *Id.* at 1.

remove Ashley's uterus.⁸³ Children's Hospital also agreed to obtain a court order prior to any other medical interventions to attenuate growth or remove the sexual organs in children with developmental disabilities,⁸⁴ and to notify WPAS about any cases in which growth attenuation procedures were requested.⁸⁵ Although the agreement applies to Children's Hospital only, the WPAS report urges global adoption of the procedures.⁸⁶

IV. LEGAL BACKGROUND: PARENTAL DECISIONS TO TREAT, TO REFUSE TREATMENT, AND TO STERILIZE

Despite the predictable reaction of the disability rights community to Ashley's treatment, Ashley's fate was decided without any legal intervention or oversight. With the exception of the removal of her uterus, a procedure that was arguably subject to mandatory court review in Washington State,⁸⁷ the absence of legal review was consistent with existing legal paradigms. Parental decisions to consent to medical interventions for their children are subject to very few legal restrictions. Even a review by a hospital ethics committee is not legally required, and the recommendations of such a committee are non-binding. The vast discretion given to parents is rooted in their constitutional right to oversee the upbringing of their children.⁸⁸

A. Parental Choice for Medical Intervention on a Child – Applicable Decisionmaking Models

A parent's right to make medical decisions for his or her child is protected by the Due Process Clause of the Fourteenth

⁸³ Press Release, David Fisher, Children's Hosp. Med. Dir., Growth Attenuation Press Conference (May 8, 2007) [hereinafter Hospital Press Release] (on file with author), available at http://www.seattlechildrens.org/home/about_childrens/press_releases/2007/05/002039.asp.

⁸⁴ CARLSON & DORFMAN, *supra* note 23, at exhibit T.

⁸⁵ Hospital Press Release, *supra* note 83, at 2.

⁸⁶ CARLSON & DORFMAN, *supra* note 23, at 7.

⁸⁷ See *In re Hayes*, 608 P.2d at 640-44 (1980); CARLSON & DORFMAN, *supra* note 23, at 19-23.

⁸⁸ *Troxel v. Granville*, 530 U.S. 57, 65-66 (2000).

Amendment.⁸⁹ This right is not absolute, but it is well-established.⁹⁰ So long as parents are fit “there will normally be no reason for the State to inject itself into the private realm of the family to question the ability of that parent to make the best decisions concerning rearing of that parent’s children.”⁹¹ The constitutional protection afforded to fit parents clothes them with a presumption that they “act in the best interests of their children”⁹² in making choices, including medical choices, for their children.⁹³ The presumption that parents act in their child’s best interests effectively shields most parental decisions about a child’s health care from scrutiny or limitation. While a court may occasionally override a parent’s decision to *refuse* treatment if the choice puts the child’s health or life at risk,⁹⁴ courts almost never intervene when a parent chooses a medically approved alternative to treat a child.⁹⁵ Thus, the law generally leaves the tough decisions to

⁸⁹ *Id.*

⁹⁰ *See id.*; *see also* *Parham v. J.R.*, 442 U.S. 584, 602, 604 (1979) (finding a “presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions,” and that “natural bonds of affection lead parents to act in the best interests of their children,” but also that this presumption only exists “absent a finding of neglect or abuse”); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (“It is cardinal with us that the custody, care and nurture of the child reside first in the parents”).

⁹¹ *Troxel*, 530 U.S. at 68-69; *see also Parham*, 442 U.S. at 602 (stating that “our constitutional system long ago rejected any notion that a child is the mere creature of the state”). Where a parent is deemed unfit, or neglectful, the state may intervene more freely. *See, e.g., 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).

⁹² *Parham*, 442 U.S. at 602.

⁹³ *Troxel*, 530 U.S. at 68-69.

⁹⁴ *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.); *see Jehovah’s Witnesses v. King County Hosp. Unit No. 1*, 390 U.S. 598 (1968) (per curiam), *aff’g* 278 F. Supp. 488 (W.D. Wash. 1967) (overriding parental refusal to provide blood transfusion where death would result without the transfusion).

⁹⁵ *E.g., Tenenbaum v. Williams*, 193 F.3d 581 (2d Cir. 1999); *In re Hofbauer*, 393 N.E.2d 1009 (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); *In re Hudson*, 126 P.2d 756 (Wash. 1942) (holding that a 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).

parents.

There are, however, exceptional laws that limit parental choice. Often aimed at a particular treatment or procedure, these laws replace the usual paradigm of parental choice with one of three decisionmaking models: child's choice, prohibition, or third-party oversight.⁹⁶ The first model, child's choice, places in the hands of the minor his or her own medical decisions. Child's choice applies to adult-like children (mature minors)⁹⁷ and decisions that involve or result from adult-like activities such as sex, drug use, or alcohol use.⁹⁸ With respect to abortion, child's choice is supported by the constitution because the child's right to reproductive freedom is at least as important as the right of the parents to familial autonomy.⁹⁹ With respect to mature minors generally, and to children who seek sex, drug, and alcohol treatment, the states that have adopted child's choice have made the policy decision that public health interests or

⁹⁶ *E.g.*, 18 U.S.C. § 116 (2000) (prohibiting anyone, including parents, from having female circumcision performed on a minor); OR. REV. STAT. §§ 109.610, 109.640 (2007) (allowing minors to consent to treatment for venereal disease or receive birth control information and services, without a parent's permission); WASH. REV. CODE § 11.92.043(5) (2007) (subjecting to judicial review parental decisions to sterilize or institutionalize a minor).

⁹⁷ Lawrence Schlam & Joseph P. Wood, *Informed Consent to the Medical Treatment of Minors: Law and Practice*, 10 HEALTH MATRIX 141, 163-66 (2000) (describing the mature minor doctrine); *see also* Cara Watts, *Asking Adolescents: Does a Mature Minor Have a Right to Participate in Health Care Decisions?*, 16 HASTINGS WOMEN'S L.J. 221, 233-36 (2005). The "mature minor" doctrine is generally a common law matter, though a few states such as Ohio and Illinois have adopted the doctrine by statute. *See* 410 ILL. COMP. STAT. ANN. 210/1 (LexisNexis 2007); OHIO REV. CODE ANN. §§ 3709.241, 3719.012, 5122.04 (LexisNexis 2008).

⁹⁸ *E.g.*, 410 ILL. COMP. STAT. ANN. 210/4 (LexisNexis 2007); N.Y. PUB. HEALTH § 2504 (McKinney 2001 & Supp. 2005).

⁹⁹ *See* Planned Parenthood of Central Mo. v. Danforth, 428 U.S. 52 (1976) (declaring unconstitutional a state statute that granted parents an absolute veto over a minor child's decision to have an abortion). In *Planned Parenthood v. Danforth*, which overturned restrictions on a minor's right to consent to abortion, the Supreme Court held that constitutional rights do not "magically" appear at the time a child reaches maturity. *Id.* at 74. The Court emphatically stated that "minors, as well as adults, are protected by the Constitution and possess constitutional rights." *Id.* The Court quickly conceded that the state has "somewhat broader authority to regulate the activities of children than of adults," but ultimately concluded that the state interest in the "safeguarding of the family unit and of parental authority . . . is no more weighty than the right of privacy of the competent minor mature enough to have become pregnant." *Id.* at 74-75. Ross Povenmire, *Do Parents Have the Legal Authority to Consent to Surgical Amputation of Normal, Healthy Tissue in their Newborn Children?: The Practice of Circumcision in the United States*, 7 AM. U. J. GENDER SOC. POL'Y & L. 87, 101 (1998).

the individual rights of the child outweigh the parents' rights to direct medical care.¹⁰⁰

The second model, legal prohibition of a particular medical intervention, is the least common. For the most part, states leave to the medical profession the task of defining what is medically reasonable or appropriate, and to parents the task of deciding among the options presented. Prohibition applies only when a particular medical procedure is deemed destructive and medically inappropriate under any circumstances. The best example of prohibition is female circumcision or clitorrectomy, a surgical procedure that is highly valued among certain cultural groups. Federal law deems the procedure female genital mutilation and makes criminal surgery on a girl's genitals that is not necessary to the health of the child.¹⁰¹ The law specifically devalues a parent's right to choose the procedure for cultural reasons.¹⁰²

Third-party oversight applies in two overlapping types of medical decisions: those fraught with the potential for abuse and those about which a parent is unlikely to be able to assess objectively the subject child's best interests. The first category includes parental decisions to sterilize children or involuntarily commit or enroll them in research protocols. The second includes parental decisions to use a child as an organ donor for a sick sibling or relative.¹⁰³ Third-party oversight takes several forms and its use varies from state to state, but—where used—the model has two common features. First, some law, regulation, or practice requires that a neutral third party review a parent's medical decision before the intervention takes place. Second, the law imposes specific criteria for when the third party can approve the use of the procedure thereby altering or eliminating the presumption that the parents' decision is reasonable. The neutral third party may or may not be a judge. Indeed, the Supreme Court has expressed a clear preference for keeping this category of cases out

¹⁰⁰ SCHLAM & WOOD, *supra* note 97, at 162-66.

¹⁰¹ 18 U.S.C. § 116.

¹⁰² *Id.* at § 116(c) (declaring that in implementing the law "no account shall be taken of the effect . . . of any belief on the part of that person, or any other person, that the operation is required as a matter of custom or ritual").

¹⁰³ 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).

of courtrooms, but has also made clear that states may decide whether a full judicial or administrative hearing is necessary.¹⁰⁴

Parental decisions to sterilize or institutionalize a minor are subject to judicial review in a majority of states, including Washington.¹⁰⁵ The Washington law at issue in the Ashley case is typical. In *In re Hayes*, the Washington State Supreme Court held that a parent of a child with developmental disability did not have authority to consent to the sterilization on behalf of her minor daughter.¹⁰⁶ The Court found that sterilization impinged significantly and permanently on fundamental liberty interests of the child in a way that most medical procedures do not.¹⁰⁷ Thus, the Court held that before sterilization could be accomplished, the child had to be represented by a disinterested third party in an adversarial hearing to determine if the sterilization was appropriate for the particular child.¹⁰⁸ The Court also reversed the presumption in favor of parental choice and held, “[t]here is a heavy presumption against sterilization of an individual incapable of informed consent that must be overcome.”¹⁰⁹ To overcome the presumption the parent would have to prove nine things by clear and convincing evidence, including the following: the child is unlikely to develop sufficiently to make an informed decision about sterilization in the foreseeable future; all less drastic methods of contraception have proved unworkable or inapplicable; and the proposed method of sterilization entails the least invasion of the body of the individual.¹¹⁰

¹⁰⁴ *Parham*, 442 U.S. at 607-09. 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 physicians 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).

¹⁰⁵ REV. CODE WASH. § 11.92.043(5) (2007).

¹⁰⁶ *In re Hayes*, 608 P.2d at 637.

¹⁰⁷ *Id.* at 639, 641.

¹⁰⁸ *Id.*

¹⁰⁹ *Id.*

¹¹⁰ *Id.*

Involuntary commitment laws vary from state to state, but they may require a neutral third-party physician to approve parental choices, or the law may require more formal judicial review to ensure that commitment is in the best interest of the particular child and that less restrictive alternatives are not available or appropriate.¹¹¹ Federal law requires Institutional Review Board (IRB) approval of research protocols involving children and places strict limitations on the types of non-therapeutic research protocols that parents may elect for their children.¹¹²

Third-party oversight applies when the health care decision to be made on behalf of a child is highly invasive, irreversible, or potentially abusive. The laws imposing third-party oversight result from a desire to prevent repetition of past abuses, such as the eugenics movement, the widespread and abusive commitment of people with developmental disabilities, and the use of children, particularly children with disabilities, in unethical research. Third-party oversight is particularly appropriate where the interests of the parent may not be the same as those of the child.¹¹³ For this reason, judges will review and occasionally intervene in cases in which a parent seeks to use the organ of a child to save the life of another person.¹¹⁴ When a parent seeks to use the kidney of one child to save the life of another, for example, the parent can hardly be expected to base the decision solely on the needs of the donor child. The parent's loyalties are split between the sick child and the potential donor child. Thus, the parent loses the benefit of the presumption and must demonstrate to a third-party that donation—an invasive and irreversible elective procedure—is in the best interests of the donor child.¹¹⁵

¹¹¹ *Parham*, 442 U.S. at 607; see also *In re Roger S.*, 569 P.2d 1286 (Cal. 1977).

¹¹² 45 C.F.R. §§ 46.401-.409 (2007).

¹¹³ See CARLSON & DORFMAN, *supra* note 23, at 19; *In re Hayes*, 608 P.2d at 641 (stating that the parents' interest in obtaining sterilization of a child with developmental disabilities cannot be presumed to be the same as the minor for whom the sterilization is sought).

¹¹⁴ For an excellent synthesis of the cases addressing the use of children as organ donors, see Michelle Goodwin, *The Politics Of Health Law: My Sister's Keeper? Law, Children, and Compelled Donation*, 29 W. NEW ENG. L. REV. 357 (2007).

¹¹⁵ In most cases, reviewing courts have held that parents have met the burden. See Tilden, *supra* note 103 (discussing both reported and unreported cases).

B. Application to Ashley's case

Ashley's case was decided using the default model of parental choice. Once her physicians agreed that the interventions her parents sought were medically and ethically appropriate options, Ashley's parents were free to consent to their implementation. With the probable exception of the removal of her uterus, that consent was all current law required.

The decisionmaking models that limit parental choice did not apply. Child's choice was not an option because Ashley had no decisionmaking capacity and did not seek treatment in one of the statutorily-defined categories that shifts decisionmaking from the parent to a child. Prohibition did not apply because no law bans the use of estrogen, hysterectomy, mastectomy, or appendectomy. Their use in Ashley's case was clearly unconventional, but like the off-label use of prescription drugs, their unconventional use was not illegal. Likewise, third-party oversight did not apply to the hormone treatment, mastectomy, or appendectomy. Third-party oversight applies to specific interventions defined by courts, legislatures, or regulatory bodies, such as sterilization, electroshock therapy, and involuntary commitment. No decisional law, statute, or regulation required third-party oversight of the hormone treatment, mastectomy, or appendectomy at the time Ashley's parents made their choice. While the hospital or physicians might have been wise to seek court approval of the proposed interventions because of their unprecedented use and Ashley's vulnerability, the law simply did not require such a step.

Third-party oversight was, however, probably required for the hysterectomy. As the ethics committee noted, Washington's highest court ruled in *Hayes* that a court order is required before a developmentally disabled person who lacks decisionmaking capacity can be sterilized.¹¹⁶ Neither the doctors involved in Ashley's case nor the hospital in which her surgery took place sought court review of the proposed hysterectomy.¹¹⁷ WPAS investigated the circumstances that allowed the surgery to go forward without court review. WPAS learned that Ashley's parents presented the surgeon with a letter

¹¹⁶ See Committee Meeting, *supra* note 32, at 3.

¹¹⁷ Hospital Press Release, *supra* note 83.

from their attorney offering his opinion that a court order was not necessary in Ashley's case.¹¹⁸ The attorney reasoned that *Hayes* was inapplicable when sterilization is not the goal of treatment but "merely a byproduct of surgery performed for other compelling reasons."¹¹⁹ In Ashley's case, he said, the hysterectomy could proceed without court involvement because it was needed for medical reasons other than the prevention of pregnancy. Ashley's surgeon and the Medical Director of Children's Hospital believed the letter satisfied the requirement for "court review."¹²⁰ The hospital explained "our medical staff and administration misinterpreted th[e] guidance from the family's lawyer as adequate 'court review.'"¹²¹

The hospital's subsequent admission that "the law is clear that a court order should have been obtained before proceeding with the hysterectomy"¹²² is probably correct. After all, Ashley's parents sought the procedure in part out of a concern that "Ashley could later be a victim of sexual abuse as has occurred all too often in neurodevelopmentally disabled teens."¹²³ The only relevance of a hysterectomy to sexual abuse is the fact that hysterectomy prevents pregnancy. Thus, one of the goals of the procedure was to sterilize Ashley, even if the primary goal was to eliminate pain and discomfort of menstruation; the argument that Ashley's sterilization was a mere byproduct of otherwise beneficial medical procedures lacks credulity. But the family attorney's argument that Washington law does not require court review of all hysterectomies in people with developmental disabilities is not untenable.¹²⁴ It is hard to

¹¹⁸ The letter is reproduced in full in CARLSON & DORFMAN, *supra* note 23, at exhibit O.

¹¹⁹ *Id.*

¹²⁰ *Id.* at 14.

¹²¹ Hospital Press Release, *supra* note 83.

¹²² *Id.*

¹²³ *Id.*

¹²⁴ The opinion letter also relies on a second line of argument that is utterly untenable. It asserts that *Hayes* and its progeny are distinguishable from Ashley's case because unlike the women in those cases, Ashley "does not know what a child is and cannot talk." CARLSON & DORFMAN, *supra* note 23, at exhibit O. Nothing in *Hayes* or its progeny suggests that the demand for procedural protections in cases of involuntary sterilization is somehow dependent on the extent of the subject person's disabilities. As stated in the WPAS report, "the amount and scope of an individual's due process and privacy rights is not on a sliding scale." CARLSON & DORFMAN, *supra* note 23, at 23.

imagine that a court order would be required, for example, if a hysterectomy or surgical removal of ovaries were necessary for the treatment of uterine or ovarian cancer in a person with disabilities. The settlement between Children's Hospital and WPAS leaves open the question of whether Washington law requires judicial review whenever a medical procedure will result in the sterilization of a person with developmental disabilities, or if such review is required only when the intent of the procedure is to prevent that person from becoming pregnant. Washington hospitals would be wise to seek court approval in any case in which a hysterectomy is sought in a child or person with developmental disabilities until the murkiness in the law is resolved.

That said, the need for court review of the hysterectomy in Ashley's case is somewhat beside the point. Such review would not necessarily have changed the outcome in Ashley's case because a reviewing court might well have found the surgery to be appropriate given its potential to minimize the risk of blood clots from the hormone therapy and the near impossibility that Ashley would ever be able to exercise her right to reproduce.¹²⁵ More importantly, the default model of parental choice applied in Ashley's case to the hormone treatment and mastectomy will continue to apply in future cases in which parents seek growth attenuation in children with profound disabilities.¹²⁶ Moreover, future cases will likely involve male children in whom sterilization will not be at issue. Thus, the need for procedural limitations on parental choice to stunt the growth of disabled children as a way to manage their disabilities remains very much at issue, even if third-party review is required to perform hysterectomies in Washington State under such circumstances.

V. ASHLEY'S RIGHTS, CHILDREN'S RIGHTS.

That current law did not limit Ashley's parents from choosing to modify their daughter's body is not the end of the discussion. Indeed,

¹²⁵ Gunther & Diekema, *supra* note 8, at 1015.

¹²⁶ Children's Hospital will voluntarily seek court approval of the use of surgical and medical growth attenuation in developmentally disabled children when such treatment is proposed in new cases. Hospital Press Release, *supra* note 83.

significant questions remain about the lack of regulation, the parents' claim that their decision to "treat" Ashley should be kept in the family, the demand for a moratorium by the disability rights community, and Children's Hospital's agreement to seek judicial review in future cases. This section addresses three of those questions: First, could a state legally regulate the set of interventions performed on Ashley? Second, does the record in Ashley's case suggest that regulation is necessary? And third, what model of regulation, if any, is appropriate? The answer to the first two questions is clearly yes. The magnitude of the actual and potential harm of the interventions, the potential conflict of interest on the part of the parents, and the potential for abuse of the interventions or ones like them are more than sufficient to justify and necessitate legal regulation of parental choice. The record in Ashley's case shows the failings of the parental-choice model and the need for regulation in future cases. That regulation should be some form of third-party review with strict criteria. Although some of the concerns that justify prohibition are present in growth attenuation cases, third-party review will better protect children with disabilities by recognizing that their lives, needs, and interests are just as individual as those of children without disabilities.

A. Legal Restraints on Parental Choice for Medical and Surgical Growth Attenuation are Justified by Its Actual and Potential Harm, the Conflicted Interests of the Parents, and Its Potential for Abuse.

Any restraint on parental choice over medical care for a child must be justified by state interests that outweigh the parents' constitutional right to make medical decisions for their child.¹²⁷ A state's interests in protecting health, safety, liberty, and privacy interests of children justify limitations on parental choice.¹²⁸ "[A]

¹²⁷ See *Parham*, 442 U.S. at 600; *In re Valerie N.*, 707 P.2d 760, 777 (Cal. 1985) (holding that California's ban on sterilization of incompetent people with developmental disabilities was unconstitutional in part because it deprived the person with disabilities the right to access reproductive choices available to people without disabilities); see also Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, 86 YALE L.J. 645, 662 (1977).

¹²⁸ *Parham*, 442 U.S. at 600; *In re Hayes*, 608 P.2d at 639; P.S. *ex rel. Harbin v. W.S.*, 452 N.E.2d

state is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized.”¹²⁹

States may therefore limit parental choice to protect a child’s “substantial liberty interest in not being confined unnecessarily for medical treatment.”¹³⁰ With respect to involuntary commitment, for example, the Supreme 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.”¹³¹

The actual harm to children posed by the irreversible and elective destruction of healthy human tissue and proper functioning of organs is even greater than the potential risks of involuntary commitment. In the case of ritual female circumcision, for example, the harm caused by the removal of healthy human tissue and destruction of sexual function without medical necessity and its attendant physical and psychological consequences justifies a federal law banning the practice altogether. That law recognizes that although a parent may seek the procedure without intending to inflict harm—parents seek the procedure for cultural and religious reasons—its damaging physical, sexual, and psychological effects make the procedure an unacceptable act of violence against women and children.¹³²

A state’s interest in protecting a child from unnecessary medical treatment is especially significant when the parents’ interests “cannot be presumed to be identical to those of the child,”¹³³ such as with

969 (Ind. 1983); *see also* *Jacobson v. Massachusetts*, 117 U.S. 11, 37-38 (1905) (endorsing compulsory child vaccination statutes over the protest of parents and children).

¹²⁹ *Parham*, 442 U.S. at 602.

¹³⁰ *Id.* at 600 (citing *Addington v. Texas*, 441 U.S. 418, 425 (1979), *In re Gault*, 387 U.S. 1, 27 (1967); *Specht v. Patterson*, 386 U.S. 605 (1967)).

¹³¹ *Parham*, 442 U.S. at 606.

¹³² *See* Dena S. Davis, *Male and Female Genital Alteration: A Collision Course with the Law*, 11 HEALTH MATRIX 487 (2001); *see also* *Winston v. Lee*, 470 U.S. 753, 764-65 (1985) (acknowledging that the use of surgery involving general anesthesia may impose significantly on a person’s personal privacy and bodily integrity).

¹³³ *In re Hayes*, 93 P.2d at 640.

involuntary sterilization¹³⁴ and sibling donation. The risks to the child are so great in such cases that the parents lose the benefit of the presumption that they are acting in their child's best interests, and instead, must prove that the desired procedures are appropriate for their child.¹³⁵

The state's interest in protecting children who are members of a class that has been subject to historic mistreatment from potentially abusive interventions also justifies limitations on parental authority. In the 1970s, for example, federal law dramatically restricted the ability of parents to enroll their children in research protocols "in response to the revelation that the consulting physician to the Willowbrook School, an overcrowded state-run home for the mentally disabled, had deliberately infected healthy children with hepatitis to learn more about the disease's etiology."¹³⁶

All of the concerns that have justified limitations on parental decisionmaking in past cases were present in Ashley's case. Without any medical reason, Ashley was confined to the hospital for four days, sliced open, and anesthetized. She received transdermal hormone treatments for over a year that impaired her normal growth functioning. She lost her breasts and her uterus, and may face long-term consequences of the untested hormone treatments. These elective, highly invasive, and irreversible procedures caused Ashley actual harm and put her at risk that was at least as significant as that caused by involuntary commitment or sibling donation.

The set of interventions used on Ashley are even comparable to female circumcision or genital cutting. Like that practice, the

¹³⁴ The fact that the sterilization cases are buttressed by the incompetent person's right to reproduce does not make the cases irrelevant to the analysis of someone like Ashley who will never be able to voluntarily engage in sexual intercourse or reproduction. To Ashley, her uterus is really no more important than her breasts. Neither organ is or will be of particular use. If a parent has the discretion to cut one out, it seems odd that the same parent must obtain court approval to remove the other. Unless a profoundly disabled child's uterus is of more value than her developing breasts, it would seem the same policy concerns that require court approval of the uterus would apply equally to removal of the breast buds.

¹³⁵ See *In re Hayes*, 608 P.2d at 640; *Parham*, 442 U.S. at 604 ("[A]bsent a finding of neglect or abuse . . . the traditional presumption that the parents act in the best interests of their child should apply").

¹³⁶ Randall Baldwin Clark, *Speed, Safety, and Dignity: Pediatric Pharmaceutical Development in an Age of Optimism*, 9 U. CHI. L. SCH. ROUNDTABLE 1, 3 (2003).

interventions used on Ashley involved the purposeful destruction of healthy tissue, organs, and functioning with no attendant physical or medical gains. The alleged benefits of both procedures are social—acceptance within cultural group for one, and the ability to remain at home with family for another. The procedures are not identical of course. Female genital cutting is correctly condemned as barbaric in the United States and internationally because of the damage it causes girls and women and because of its utter lack of utility. Growth attenuation may well have more social benefits than female genital cutting, but the similarities between the procedures should not be ignored.

Moreover, Ashley's parents' interests cannot be presumed to be identical to those of Ashley. Just as with parents who seek to sterilize their sexually active but developmentally disabled daughters or those who seek to donate organs of a healthy child to benefit a sick child, Ashley's parents had much to gain by changing Ashley's body. Simply put, their lives would be made better if they modified Ashley. They would be relieved of the burden of caring for a profoundly needy adult-sized being. They would no longer need to strain to carry Ashley. They would not have to deal with her menstrual blood or see their "pillow angel" develop adult breasts that they saw as incompatible with her mental development. They could keep strangers out of their home and avoid the guilt and loss felt by many parents who have to institutionalize their children. They could spend more time and money on their "healthy"¹³⁷ children because Ashley would require less physical attention.

That Ashley's parents and family would benefit from the interventions does not mean that Ashley would not also benefit from the procedures. Nor does it mean that the parents were selfish for seeking them. Just as sibling donation may be in the best interest of the donor child for whom the intervention is not therapeutic and the benefits only social, the interventions may well have been in Ashley's best interests. Indeed, her parents and doctors are convinced that she is better off for having had them because she is lighter, more transportable, and perhaps less likely to suffer from bed sores and

¹³⁷ Parents' Blog, *supra* note 5. The parents' description of Ashley's brother and sister as "healthy" suggests that Ashley was unhealthy. The intimation is troubling. Ashley was not sick when she was modified. A person living with disabilities can be perfectly healthy.

scoliosis than she would be had her growth not been stunted. The problem is that the default process used in Ashley's case presumed Ashley's parents were in the best position to decide if the interventions were in fact in Ashley's best interests. The potential benefits to Ashley's parents created a conflict of interest that would justify, and even require, an entirely neutral advocate and decisionmaker for Ashley.

The interventions used on Ashley are also so fraught with the potential for abuse that a state could restrict their use on that basis alone. To be sure, growth attenuation is without the historical legacy of research abuses, eugenics, and involuntary commitment. And there is no hint of abuse in Ashley's case, the only documented case of its use. But one can imagine widespread use of medical and surgical growth attenuation by parents who simply want to minimize the burden of raising a disabled child or the cost of care. This country's mistreatment of people with disabilities like Ashley's suggests that these possibilities are not far-fetched, and that a state has a significant interest in preventing their realization.

Given the significant risks to children, the questionable ability of the parents to serve as the advocate of the child's best interests, and the potential for abuse, a state or regulatory body could lawfully impose limitations on parental discretion to medically and surgically stunt a developmentally-disabled child's growth. A review of the decisionmaking process in Ashley's case emphasizes why such limitations are necessary.

B. The Process Failures in Ashley's Case Show Why Legal Restraints on Parental Choice Are Necessary To Protect Children.

While parental choice is the preferred model when a medical decision must be made for a child, it is not the best model for decisionmaking about surgical and medical growth attenuation. The absence of a medical need for intervention, the permanent nature of change in the child, the unknowable risks of untested interventions, the parents' conflict of interest, and the obvious potential for abuse change the equation entirely. Just as with involuntary commitment, sterilization, or enrollment in non-therapeutic research protocols, some limitation of parental discretion is required to ensure that

children with disabilities are adequately protected when their parents seek to attenuate their growth through medical and surgical intervention for social, not medical, reasons.

A review of the decisionmaking process in Ashley's case supports the argument that parental choice is a deficient decisionmaking model. Ashley's is a good case study because it is a poignant example of the parental choice model. Before her surgery, Ashley's parents consulted extensively with thoughtful and well-regarded physicians to come up with a treatment plan that met her needs. There is no indication in any of the records that these parents were in any way unfit, abusive, or neglectful. To the contrary, they appear to have acted at every step in good faith, with love, and with good intentions. Ashley's mother researched the possible options for Ashley. She proposed a set of interventions to Ashley's doctors. Both parents voluntarily sought review by an ethics committee, which met with them for an hour. Presumably, they would have complied with a committee recommendation, had the committee recommended against the procedures. The ethics committee served as a sounding board for Ashley, her parents, and their doctors. The Committee had no conflicts of interest. It debated the proposed treatment plan and issued its opinion. The decision in Ashley's case was thoughtful and careful.

Nonetheless, the decisionmaking process was inadequate. It failed to put on the table everything that was at stake for Ashley, or to adequately explore less invasive options. Moreover, it ultimately left the decision of whether to proceed with the interventions in the parents' hands, despite the real possibility that their interests were not identical to Ashley's.

The discussions in Ashley's case among the parents, doctors, and ethics committee focused extremely narrowly on the *potential* physical risks of the proposed procedures to Ashley without adequate consideration of actual physical harm or harm beyond the physical. The only risks the Committee identified from the hormone treatment were "increased potential for deep vein thrombosis, possible weight gain, and possible nausea."¹³⁸ For the hysterectomy, the risks included "anesthesia, surgery, and post-operative recovery

¹³⁸ Committee Meeting, *supra* note 32, at 2.

period, with the additional short term discomfort and suffering,"¹³⁹ and essentially no risk from the mastectomy "with the patient's breast development being rudimentary."¹⁴⁰

The Committee appears to have discounted entirely the physical harm the procedures would necessarily involve. It is as though the loss of a uterus, the removal of breasts, and the intentional disabling of normal growth had no significance or value. But these physical losses were in no way inconsequential. In any other context the removal of healthy, functioning tissue and organs, and the purposeful stunting of healthy, normal growth would be considered abusive. Gunther and Diekema argued in their paper that being small was not harmful to Ashley because she could not appreciate height.¹⁴¹ Her parents argue on their blog that the loss of Ashley's uterus and breasts was not harmful because she could not "use" them.¹⁴² These arguments demand close evaluation before they are accepted, and the Committee's failure to even address the possibility that the physical losses were meaningful is troubling.

Physical losses may cause devastating but intangible injuries to an individual, and the use of physical modifications to manage a vulnerable population could have grave social consequences. No one raised these concerns on Ashley's behalf. Specifically, no one argued that stunting Ashley's physical growth to keep her perpetually childlike would disturb what Fukuyama calls our human essence.¹⁴³ No one argued that less invasive alternatives were preferable in order to do everything possible to advance Ashley's right to an open future.¹⁴⁴ No one considered that elective growth attenuation might

¹³⁹ *Id.*

¹⁴⁰ *Id.* at 3.

¹⁴¹ Gunther & Diekema, *supra* note 8, at 1015.

¹⁴² Parents' Blog, *supra* note 5.

¹⁴³ FRANCIS FUKUYAMA, *THE END OF HISTORY AND THE LAST MAN* 130,172 (1992) (describing human essence as "the sum of human unity and continuity," something that ought not be destroyed); *see also* GREGORY STOCK, *REDESIGNING HUMANS: OUR INEVITABLE GENETIC FUTURE* 19-34 (2002).

¹⁴⁴ Joel Feinberg argues that the right to an open future arises from the right to self determination and to bodily integrity. *See* JOEL FEINBERG, *THE CHILD'S RIGHT TO AN OPEN FUTURE*, IN *FREEDOM & FULFILLMENT* 84 (1992); *see also* EAMON CALLAN, *CREATING CITIZENS: POLITICAL AND LIBERAL DEMOCRACY* 68 (1997); Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on*

create a permanent underclass.¹⁴⁵ No one argued that a child simply has a right to all her healthy organs and to grow without deliberate interference. No one discussed the ways in which human difference is valuable, or the evidence generated by the disability rights community demonstrating the inability of parents and others without disabilities to comprehend the value of life with disability, or the inability of able-bodied parents to make truly informed decisions for their children without adequate education.¹⁴⁶ And no one considered the experience of other vulnerable groups of children, like intersex children who were subject to genital “normalization” surgery for non-medical, social reasons.¹⁴⁷ The literature documenting the tragic aftermath of genital normalizing surgery on the intersexed identifies frank and unintended dangers of using irrevocable elective surgery for social reasons.¹⁴⁸ The failure of the Committee to consider such intangible injuries left Ashley vulnerable to harm that should have been identified before she was subjected to surgical modification.

It is further unclear whether the Committee made any effort to explore the possibility of a less restrictive and invasive alternative. Disabilities theorists make compelling arguments that societal solutions must be implemented before medical modifications are made to a person with disabilities.¹⁴⁹ In Ashley’s case, there is no evidence that the Committee considered the possibility of modifying the strap on the wheelchair that would have crossed over Ashley’s breasts before it approved removing her breasts to make the strap

Infants with Ambiguous Genitalia?, 7 MICH. J. GENDER & L. 1, 56-59 (2000).

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ *Id.*

¹⁴⁸ See e.g., Beh & Diamond, *supra* note 144 (documenting long term depression, incidents of suicide, and other negative consequences for children who experienced genital normalization surgery.) See also, ERIK PARENS, SURGICALLY SHAPING CHILDREN: TECHNOLOGY, ETHICS, AND THE PURSUIT OF NORMALITY (2006) (exploring personal accounts and the scholarly data on the long term consequences of shaping surgeries).

¹⁴⁹ See generally Mike Oliver, The Individual and Social Models of Disability, Paper Presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians (July 23, 1990), available at <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/in%20soc%20dis.pdf> (discussing the social model of disability, which suggests societal rather than medical changes should be implemented for the benefit of disabled persons); MICHAEL OLIVER, THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH (1990).

more comfortable.¹⁵⁰

Ashley needed an advocate. The Committee's narrow focus on certain physical risks of the proposed interventions was especially perplexing because no medical problem triggered the need for a decision in Ashley's case.¹⁵¹ Unlike the usual case in which the risks of intervention are balanced against the risks of inaction, neither the Committee nor the doctors identified a single tangible risk in allowing Ashley's growth to continue normally.¹⁵² Instead, the focus was on social benefit of intervention.¹⁵³ Ashley would be easier to care for.¹⁵⁴ She could spend more time with her family. She would be less of a target for sexual abuse.¹⁵⁵ That focus told only one side of the story. Someone needed to raise the social and moral risks of intervention. An advocate for Ashley could have pointed out, for example, the possibility that Ashley will face increased stigma because of her unnaturally small size and childlike body. Future caregivers, peers, and acquaintances might react more negatively to an unnaturally stunted woman than to a full-grown woman with disabilities. An advocate could also have pointed out that the interventions would expose Ashley to what disability activists view as dehumanizing manipulation. The specter of indignity and attendant moral harm needed airing; to the extent the interventions impaired Ashley's healthy bodily functions to serve third parties, Ashley suffered the moral harm that results when a person is denied full human respect. Inclusion of an advocate for Ashley in the conversation would have helped to ensure greater scrutiny of all the potential social and moral consequences of the interventions.

The apparent failure of the Committee and the parents to explore social, psychological, and moral harm is especially troubling in Ashley's case because they are the very harms that have historically been inflicted on persons with disabilities. Ashley's case would not have arisen if she had not been disabled. It is unthinkable that any

¹⁵⁰ See generally Committee Meeting, *supra* note 32.

¹⁵¹ *Id.*

¹⁵² *Id.*

¹⁵³ *Id.*

¹⁵⁴ *Id.* at 3.

¹⁵⁵ *Id.*

physician would agree to stunt the growth of a child and remove her breasts and uterus if that child did not have profound disabilities that had already limited her mental growth and rendered her breasts and uterus essentially unusable. Thus, the charge by the disability community that Ashley's is a disability case is right on.

That Ashley's was a disability case is concerning. It does not, however, make the treatment she received illegal disability discrimination, as claimed by some people in the disability rights community. Medicine must recognize and act on physical difference. Such is the nature of the discipline. The physical difference might be the presence of an infection. It is medically appropriate to prescribe an antibiotic for someone who has an infection, for example, but medically inappropriate to prescribe the same medicine in someone who has no infection. So, too with disability: it may be appropriate to treat a diabetic with insulin, a quadriplegic with a breathing tube, or a child with down-syndrome-related heart malformation with heart surgery. The physical difference creates a need the treatment addresses—insulin, a breathing tube, or heart surgery—and a physician can provide the treatment without being guilty of unlawful discrimination.

In Ashley's case, the interventions were not disability discrimination any more than the insertion of a breathing tube in a quadriplegic would be. They were designed to address needs created by her physical difference. But the fact that the interventions were permissible in Ashley only because of her disabilities should trigger special scrutiny and limitations to minimize the harm they could cause. Procedural limitations—including the imposition of strict guidelines to ensure consideration of all possible harm to the disabled child—are therefore needed before anyone may elect to modify a child's body to manage his or her disabilities.

C. Binding Third-Party Review Limited by Strict Criteria – Not Prohibition – Is the Best Model for Cases of Proposed Growth Attenuation

The existence of important state interests does not justify all types of limitations on parental choice. Instead, the limitations should be tailored to serve the competing interests of the child and the parent. With respect to surgical and medical growth attenuation, the

disability community's call for prohibition goes too far.

Prohibition is neither wise nor necessary to protect children. The outright prohibition of a particular medical procedure is appropriate only when the subject intervention is unacceptable for everyone. In the case of the federal ban on female genital mutilation, for example, the government has decided that the procedure is never medically appropriate and therefore not legal in any case.¹⁵⁶ Prohibition is more problematic if the prohibition applies only to people with disabilities.

A law that prohibits people with disabilities from accessing a particular medical intervention that is available to those without disabilities may be unconstitutional under the Americans with Disabilities Act (ADA). The ADA provides that "[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation."¹⁵⁷ The ADA also forbids "utilizing standards, criteria, or methods of administration that have the effect of discrimination on the basis of disability."¹⁵⁸ Medical care clearly falls within the scope of the ADA.¹⁵⁹ Under the ADA, a disabled person is entitled to all the medical care that would be provided to a nondisabled person.¹⁶⁰ For example, an HIV-infected woman

¹⁵⁶ 18 U.S.C. § 116.

¹⁵⁷ 42 U.S.C. § 12182 (2000).

¹⁵⁸ *Id.* § 12112(b)(3)(A).

¹⁵⁹ See, e.g., *Bragdon v. Abbott*, 524 U.S. 624 (1998) (applying ADA in medical treatment case involving a dentist).

¹⁶⁰ E.g., *In re Baby "K"*, 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993), *aff'd on other grounds*, 16 F. 3d 590 (4th Cir. 1994) (requiring hospital to provide life support to anencephalic infant). The most significant victory came not from the courts, but from a decision by the Health and Human Services Secretary to block the Oregon health care rationing plan on grounds it would violate the antidiscrimination laws. Letter from Louis W. Sullivan, Sec'y of Health & Human Servs., to Barbara Roberts, Governor of Or. (Aug. 3, 1992) (with accompanying three-page "Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration"), reprinted in *ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 409-12 (1994). Advocates have also had some court victories. See, e.g., *Henderson v. Bodine Aluminum, Inc.*, 70 F.3d 958, 960 (8th Cir. 1995) (finding in a case of an insurance denial for a bone marrow treatment that "if the evidence shows that a given treatment is non-experimental—that is, if it is widespread, safe, and a significant improvement on traditional therapies—and the plan provides the treatment for other conditions directly comparable to the one at issue, the denial of that treatment arguably violates the ADA"); *Carparts Distrib. Ctr., Inc. v. Auto. Wholesaler's Ass'n of New Eng.*,

successfully sued under the ADA to force a dentist to fill her cavity in his office instead of in the hospital,¹⁶¹ and the mother of an anencephalic infant was able to use the ADA to force a hospital to keep her baby alive through ventilation.¹⁶² The courts in these cases reasoned that treatment available to the nondisabled must be available to the disabled.¹⁶³

Under the same reasoning, a ban on the use of hysterectomy, mastectomy, or hormone treatment in the developmentally disabled would likely violate the ADA because these procedures are available for people without disabilities. That their use is motivated by social and not medical concerns in cases like Ashley's makes no difference so long as a nondisabled person could choose a hysterectomy, a mastectomy, or hormone treatments for social reasons. Such a prohibition would also raise equal protection concerns. For example, the California Supreme Court ruled that a total ban against the sterilization of people with developmental disabilities was unconstitutional because it denied people with disabilities the ability to control their reproductive rights in the same manner as other people.¹⁶⁴ The court concluded that:

True protection of procreative choice can be accomplished only if the state permits the court-supervised substituted judgment of the conservator to be exercised on behalf of a conservatee who is unable to personally exercise this right. Limiting the exercise of that judgment by denying the right to effective contraception through sterilization to this class of conservatees denies them a right held not only by conservatees who are competent to consent, but by all other women.¹⁶⁵

The same rationale applies to the set of interventions used on Ashley. Banning their use in people with disabilities might be as discriminatory as forcing them on people with disabilities.

Third-party review is a better model for decisions to attenuate a child's growth. More than prohibition, third-party review treats

Inc., 37 F.3d 12 (1st Cir. 1994) (applying ADA to denial of health coverage by employer health plan).

¹⁶¹ *Bragdon*, 524 U.S. at 648-54.

¹⁶² *In re Baby "K"*, 832 F. Supp. at 1028-29.

¹⁶³ *See id.* at 1029.

¹⁶⁴ *In re Valerie N.*, 707 P.2d 760 (Cal. 1985).

¹⁶⁵ *Id.* at 777.

people as individuals with unique needs, lives, and values. It balances the competing interests between parents and children, and leaves the medical establishment to decide what treatment options are appropriate. In this way, third-party review ensures adequate protection for vulnerable populations without foreclosing access to what might in a particular case be a medically appropriate treatment. It is flexible. It can be structured to curtail the availability of a particular option, or simply to serve as a check on the decision that the proposed intervention serves the particular child's best interest.

The precise contours of third-party review in growth attenuation cases may be determined by the states' legislatures or regulating agencies. It may, but need not require court involvement. Some commentators argue against the involvement of courts in medical decisions:

[T]here is no basis for assuming that the judgments of its decision makers about a particular child's needs would be any better than (or indeed as good as) judgments of his parents. Only magical thinking will permit the denial of these self-evident, but often ignored, truths about the limits of law.¹⁶⁶

Parnam also teaches that reliance on professionally-trained neutral fact finders may adequately protect children's rights when coupled with statutory criteria:

It is one thing to require a neutral physician to make a careful review of the parents' decision in order to make sure it is proper from a medical standpoint; it is a wholly different matter to employ an adversary contest to ascertain whether the parents' motivation is consistent with the child's interests.¹⁶⁷

On the other hand, a particular state or hospital could "elect to provide such adversary hearings in situations where [they] perceive that parents and child may be at odds."¹⁶⁸ Thus a state or regulatory agency could require review by a judge, an administrative body, a hospital committee, or some other neutral decisionmaker.

For the review to be effective, however, certain minimal

¹⁶⁶ Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, 86 YALE L.J. 645, 650 (1977).

¹⁶⁷ *Parnam*, 442 U.S. at 610.

¹⁶⁸ *Id.*

components are critical. As demonstrated by Ashley's case, the child at issue must be represented by someone other than a parent. That representative should be charged with exploring the impact of the proposed interventions in a global and comprehensive manner that takes into account both the social gains the interventions can achieve and the potential for harm as identified by disability scholars. Moreover, the interventions should be authorized only if the parent seeking them shows: (1) the interventions are actually in this child's best interests; (2) that the same goals cannot be achieved by less intrusive means; (3) that the interventions carry with them no more than the minimal risk acceptable for non-therapeutic research on children;¹⁶⁹ (4) that the intervention cannot wait until the child has developed; and (5) that no temporary solutions are available to achieve the same ends.

The settlement between Children's Hospital and WPAS is a good first step toward more appropriate decisionmaking in future cases like Ashley's. The settlement requires notification of disability rights groups, appointment of an advocate for the child, review by an ethics committee, and court approval of the proposed intervention. It is deficient in the absence of strict criteria defining when surgical and medical growth attenuation treatment is appropriate, but because the settlement provides for court review, the strict criteria set forth in *Hayes* will apply as a matter of course to cases involving hysterectomy. The same criteria should apply as a matter of policy to the hormone treatment and mastectomy because those procedures raise many of the same concerns raised by hysterectomy for a child with profound disabilities.

VI. DISABILITY-SENSITIVE DECISIONMAKING: RESTRAINING PARENTAL DISCRETION TO SURGICALLY MANAGE DISABLED CHILDREN

While the law currently allows parents a great deal of flexibility in choosing among medical interventions for a child, states may limit

¹⁶⁹ 45 C.F.R. § 46.404 (2007); *Grimes v. Kennedy Krieger Institute*, 782 A.2d 807 (Md. 2001); Benjamin Freedman et al., *In Loco Parentis: Minimal Risks As An Ethical Threshold For Research Upon Children*, 23 HASTINGS CENTER REP., Mar.-Apr. 1993, at 13, 13-19.

parental choice to protect children. At the time Ashley's case presented itself in Seattle, no state had limited parental discretion to stunt a child's growth for medical or surgical reasons. Thus, her parents were free to decide that she would be better off in a child-sized body, with surgically removed uterus and breasts.

A close look at Ashley's case reveals the magnitude of the actual and potential harm done to Ashley, such as the real possibility that her parents' own interests made inappropriate the deference they received in the decisionmaking process, and the potential that similar interventions could be abused in future cases. These concerns, and their likely re-emergence as other parents seek similar modifications of their disabled children, both justify and necessitate procedural protections for children. That such interventions would only be considered for a child with profound disabilities deepens the need for their careful and restricted use.

Hospitals, legislatures, or regulators should require third-party review of any case in which a parent seeks to use Gunther and Diekema's "new approach"¹⁷⁰ to manage a child with disabilities. The third party may or may not be a court, but the importance of the decision requires that the child be represented by someone other than a parent, and that the decisionmaker be guided by strict criteria designed to minimize potential harm and abuse.

It is not clear whether imposition of third-party review would have stopped Ashley's parents from modifying her body in the way they did. It seems likely that, at a minimum, the mastectomy would have been delayed until it was clear that Ashley had in fact developed large uncomfortable breasts, something that was merely speculative at the time of her surgery. It is certain, however, that imposition of limitations and process in her case would have gone a long way toward reducing the risk that the procedures caused Ashley more harm than any benefits they achieved. Obviously, time cannot be turned back for Ashley, but future cases can and should be regulated more carefully.

¹⁷⁰ Gunther & Diekema, *supra* note 8.