GROWTH ATTENUATION IN THE PROFOUNDLY DEVELOPMENTALLY DISABLED: A THERAPEUTIC OPTION OR A SOCIOECONOMIC CONVENIENCE?

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I. INTRODUCTION

During the first half of the twentieth century the eugenics movement fostered a belief in the possibility of a utopian race. Driven by Darwinian theories, the movement ultimately resulted in some of the most invidious treatment of disabled individuals our country has ever witnessed.[1] While the civil rights movement in the 1940s and the recent enactment of the Americans with Disabilities Act helped advance the development of the law against disability discrimination, we still lack clear guidance on the

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[1] *See* PHILIP R. REILLY, THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES, 30–40 (1991).

appropriate medical treatment of, or prophylactic interventions on behalf of, disabled individuals.[2]

The recent controversies surrounding Ashley, a little girl from Washington who was born with static encephalopathy,[3] epitomizes the challenges of making good decisions for the disabled. While she has no physical deformities, it is projected that Ashley will never mentally develop beyond the age of an infant.[4] Despite her normal physical health[5] and her lack of external deformities, she has been unable to learn or perform any voluntary physical task.[6] At the young age of six she began to experience the early stages of puberty.[7] At this time, Ashley's parents and doctors devised a plan to have her undergo a series of radical procedures aimed at preventing her from any continued natural physical development. These procedures involved a number of interventionary procedures to stunt her growth and prevent her from physically maturing into a woman.[8] Ashley is the first documented case of a

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[2] *See id.*

[3] Pacific West Maternal and Child Health Distance Learning Network, Nutrition For Children With Special Health Care Needs, http://depts.washington.edu/pwdlearn/web/glossary/glossary.htm (last visited Nov. 13, 2007) (defining static encephalopathy as "encephalopathy (brain abnormality) that will not progressively worsen").

[4] Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRICS & ADOLESCENT MED. (Oct. 2006) ("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.").

[5] The "Ashley Treatment," http://ashleytreatment.spaces.live.com/blog/ (last visited Feb. 5, 2007). Ashley's health has been referred to as normal by her parents despite her mental disability. The term relates solely to the external physical development of her body. Remaining consistent with this approach, references to Ashley's perfectly normal health will not account for her static encephalopathy. ("Ashley is a beautiful girl whose body is developing normally with no external deformities; see photos. She is expected to live a full life and was expected to attain a normal adult height and weight."). *Id.*

[6] *See id.* ("Now nine years old, Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way.").

[7] Alan Greene, Early Puberty, http://www.drgreene.com/21_1075.html (last visited May 12, 2008) ("[Early or] precocious puberty is often defined as the onset of true puberty before 8 years of age in girls . . . . Precocious puberty is 10 times more common in girls than in boys. Most precocious puberty is simply early maturation.").

[8] Gunther & Diekema, *supra* note 4, at 1014. ("[A] plan was devised to attenuate growth by using high-dose estrogen and to reduce the long-term complications of

severely mentally disabled minor being subjected to these combined procedures, now referred to as "Ashley's Treatment." The revelation of this radical and experimental course of action inspired ongoing legal, ethical, and moral debates that will undoubtedly shape the rights and care of the severely mentally disabled in the future.

Continuing to permit the unregulated growth attenuation of disabled individuals will assuredly lead to the expansion of these procedures, resulting in the degradation of mentally disabled people. Absent legislative action, invasive procedures such as those performed on Ashley will continue. Additionally, others similarly situated to Ashley's parents will be allowed, or perhaps eventually even required, to perpetually infantilize disabled children as "Pillow Angels."[9]

While it is a long-standing tradition in American society to acknowledge parental autonomy in child-rearing decisions,[10] this power is not without limits.[11] The *parens patriae* doctrine[12] permits

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puberty in general, and treatment adverse effects in particular, by performing pretreatment hysterectomy."); The "Ashley Treatment," *supra* note 5.

> It was obvious to us that we could significantly elevate Ashley's adult quality of life by pursuing the following three goals: 1—Limiting final height using high-dose estrogen therapy. 2—Avoiding menstruation and cramps by removing the uterus (hysterectomy). 3—Limiting growth of the breasts by removing the early breast buds.

Id.

[9] The "Ashley Treatment," *supra* note 5 ("She is tube fed and depends on her caregivers in every way. We call her our "Pillow Angel" since she is so sweet and stays right where we place her—usually on a pillow.").

[10] "Parents enjoy a well established legal right to make important decisions for their children." Newmark v. Williams, 588 A.2d 1108, 1110 (Del. 1991). "The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. This primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition." Wisconsin v. Yoder, 406 U.S. 205, 232 (1972).

[11] Prince v. Massachusetts, 321 U.S. 158, 165 (1944).

> Against these sacred private interests, basic in a democracy, stand the interests of society to protect the welfare of children, and the state's assertion of authority to that end, made here in a manner conceded valid if only secular things were involved. The last is no mere corporate concern of official authority. It is the interest of youth itself, and of the whole community, that children be both safeguarded from abuses and given opportunities for growth into free and independent well-developed men and citizens.

Id. See Newmark, 588 A.2d at 1108.

state intervention to protect society's youngest and most vulnerable members. When reviewing the compelling reasons set forth by Ashley's parents and doctors justifying the invasive procedures Ashley endured, it becomes equally, perhaps even more, important to consider the precedent being set regarding administration of these types of procedures on disabled minors.

There is little question that advances in medical technology help to prolong and improve the quality of life for those with access to them. At the same time our moral, ethical, and legal responsibilities regarding the application of these advancements create reason for debate. Areas of dispute range from the appropriateness of employing radical medical options to allowing them to be refused, even if they would be life saving.[13] The individual characteristics of patients generally complicate the analysis even further. Whether or to what extent age, mental capacity, disability, and other personal characteristics should affect treatment decisions is an issue which raises both moral and legal questions.

Most challenging is understanding the constitutional autonomy-based rights of the profoundly mentally disabled and subsequently enabling them to exercise these rights. It is paradoxical to question how these rights can be applied to one who is not now, and possibly has never been, competent enough to exercise them.[14] Nonetheless, it is imperative to consider these rights because the administration of radical procedures on mentally disabled children will undoubtedly affect their autonomy-based rights throughout the remainder of their lives.

This article will explain the specific implications of allowing radical palliative[15] medical procedures to be performed on mentally disabled children similarly situated to Ashley. It will

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[12] BLACK'S LAW DICTIONARY 511 (2nd Pocket ed. 2001) ("A doctrine by which a government has standing to prosecute a lawsuit on behalf of a citizen, esp. on behalf of someone who is under a legal disability to prosecute the suit . . .").

[13] *See* Cruzan v. Dir., Missouri Dep't of Health, 497 U.S. 261 (1990).

[14] *See* Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37 (2004).

[15] *See* Duane M Cady, Palliative Care and End-of-Life Care, http://www.ama-assn.org/ama1/pub/upload/mm/471/bot5A06.doc ("Palliative care focuses on management of pain and other unpleasant symptoms rather than targeting treatment towards the disease(s) causing these symptoms.").

begin with a description of growth attenuation therapy and its historical use. Next, it will provide an in-depth account of the procedures performed on Ashley and the arguments made by her parents and doctors to justify the use of each of these procedures before both the hospital's ethics committee and the public at large. This article will then discuss Ashley's rights as both a minor and a disabled individual, and analyze how these rights have been affected by the medical procedures she has been subjected to ("Ashley's Treatment"). Subsequently, it will address the public debate catalyzed by Ashley's Treatment, and Doctors Gunther and Diekema's suggestion that it become an option for similarly situated disabled children.[16] Finally, this article concludes that state legislatures need to establish clear guidelines based upon a "best interest" test prior to the performance of this radical treatment on mentally disabled children so that their health and welfare are adequately protected.

II. WHAT IS GROWTH ATTENUATION?

Growth attenuation is a process by which a high dose of estrogen is administered to a patient in order to permanently halt their physical growth.[17] When applied in the proper dosage, estrogen can effectively inhibit growth by accelerating it.[18] The process is based on what happens during puberty—the hormones introduced during puberty accelerate growth while simultaneously hastening the fusing of the epiphyseal plates of the bones. Thus, the administration of estrogen treatment increases the fusion of the epiphyses, thereby attenuating the long term projected growth of the patient.[19] This treatment, which has been around since the 1940s,[20] can serve many purposes. Initially, hormone treatment was

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[16] *See* Gunther & Diekema, *supra* note 4, at 1017.

[17] *See id.* at 1013.

[18] Jean-Pierre Bourguignon, *Linear Growth as a Function of Age at Onset of Puberty and Sex Steroid Dosage: Therapeutic Implications,* 9 ENDOC. REV. 467 (1988) ("Puberty plays a dual role in growth: height velocity is markedly accelerated while the rate of skeletal maturation is also increased with resultant fusion of epiphyseal cartilages."); *See* Gunther & Diekema, *supra* note 4, at 1014.

[19] *See* Bourguignon, *supra* note 16, at 477.

[20] *See* Joyce M. Lee & Joel D. Howell, *Tall Girls: The Social Shaping of a Medical Therapy,* 160 ARCHIVES PEDIATRICS & ADOLESCENT MED. 1035 (Oct. 2006).

administered to those "at risk for tall stature due to acromegaly."[21] This treatment successfully attenuated growth with notably minor side affects which included headaches, nausea, and weight gain.[22] Upon the successful use of estrogen therapy on patients with acromegaly, physicians began to explore new uses for this treatment.[23]

While evaluating new possibilities for the use of this treatment, it was determined that the effect of overall growth reduction would have favorable social consequences for girls projected to be taller than average.[24] Historically, American society has not been accepting of those referred to as "constitutionally tall" girls.[25] The role of a woman during the 1950s was primarily that of mother and homemaker.[26] American society placed great social pressure on girls to find a mate and fulfill this role.[27] As a result, girls projected to be abnormally tall, and their parents, found the prospect of reducing their overall growth potentially desirable.[28] Though this stigma has decreased in more modern times and the use of estrogen treatment has been reduced drastically, it still exists today.[29] Social perceptions have changed since the 1950s and the average projected height of girls for whom this treatment is believed suitable has increased exponentially.[30]

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[21] *See id.* MayoClinic.com, Diseases and Conditions - Acromegaly, http://www.mayoclinic.com/health/acromegaly/DS00478 ("Acromegaly is an uncommon hormonal disorder that develops when your pituitary gland produces too much growth hormone . . . . When this happens, your bones increase in size, including those of your hands, feet and face. The term 'acromegaly' is derived from the Greek words for extremities and enlargement.").

[22] *See* Gunther & Diekema, *supra* note 4, at 1015.

[23] *See* Lee & Howell, *supra* note 20, at 1035–36.

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

[25] *See* Lee & Howell, *supra* note 20, at 1036.

[26] *See id.*

[27] *See id.*

[28] *See* Gunther & Diekema, *supra* note 4, at 1014.

[29] *See id.* at 1014–15.

[30] *See* Lee & Howell, *supra* note 20, at 1038.

> For the initial clinical report from 1956, a height prediction of approximately 175 cm. (5 ft. 9 in.) was an indication for treatment, whereas in 1977, therapy was indicated for predicted adult height of 180 cm. (5 ft. 11 in.) according to the majority of clinicians. In comparison, by 1999, some clinicians required a predicted adult height of 188 cm. (6 ft. 2 in.) before starting therapy.

Traditionally this treatment has been used primarily on patients who have entered or surpassed their adolescent phase of development.[31] Thus the administration of this treatment to young children is an area of uncertainty and it can be classified as experimental at best.[32] Some of the risks associated with this treatment include the possibility of blood clots and deep vein thrombosis,[33] which can cause immense pain; pulmonary embolism, which may ultimately result in death;[34] as well as possible adverse effects on the future fertility of young children receiving this treatment.[35] The question is whether the goals being sought in utilizing this treatment outweigh any possible risks. Who should make this value judgment—parents or physicians? Inevitably, the child will become an adult, who may or may not have the mental capacity for independent judgment. The question will then become whether the decisions of the parents and physicians resulting in irrevocable effects will interfere with the now-adult's autonomy-based rights.

III. HISTORY OF ASHLEY'S TREATMENT

While Ashley had a typical and seemingly healthy birth,[36] she soon displayed severe developmental problems.[37] She never learned how to utilize and control her body despite her otherwise normal physical development. None of the numerous neurologists, medical geneticists, and developmental

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Id. (footnotes omitted).

[31] *See* Gunther & Diekema, *supra* note 4, at 1015; Brosco & Feudtner, *supra* note 24, at 1077.

[32] *See* Gunther & Diekema, *supra* note 4, at 1015; Brosco & Feudtner, *supra* note 24, at 1077 ("While there are data that high-dose estrogen treatment will make extremely tall-for-age (but otherwise normal) girls shorter as adults, this effect may be different in the population of children with severe disabilities. More needs to be known.").

[33] *See id.*

[34] *See* Vascular Disease Foundation, Deep Vein Thrombosis: What is it?, http://www.vdf.org/DVT/ ("When an embolus travels from the legs or pelvic areas and lodges in a lung artery, the condition is known as a "pulmonary embolism," or PE, a potentially fatal condition if not immediately diagnosed and treated.") (last visited Oct. 25, 2007).

[35] *See* Gunther & Diekema, *supra* note 4, at 1015.

[36] *See* The "Ashley Treatment," *supra* note 5.

[37] *See id.*

pediatricians[38] who examined her was able to identify a definitive cause for her developmental problems.[39]

Ashley's doctors labeled her condition "static encephalopathy of unknown etiology,"[40] which means that she has a brain malfunction of unknown cause and for which there is essentially no hope of improvement.[41] It is projected that Ashley will never mature beyond the mental state of an infant.[42] Despite the problems with her mental development, the rest of her body has developed normally with no signs of disability.[43] Ashley continues to reside with her parents and siblings[44] where she is included in family activities and attends a special education school tailored to her needs.[45]

Ashley's care was initially manageable in her family home because of her small stature. At the age of approximately six and one half years, however, there were signs that Ashley was beginning to go through the early stages of puberty.[46] At this time, her parents expressed their concerns to her doctors about her long-term care and continued physical development, and inquired about possible options.[47] One of her parents' biggest fears was that Ashley's continued growth would render them incapable of caring for her at home, forcing them to surrender her care to strangers.[48] Additionally, her parents expressed concern about the impact that puberty would have on Ashley, namely menstruation and the development of breasts.[49] Because Ashley has the mental capacity of an infant, her parents believed menstrual cramps and breasts,

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[38] *See* Gunther & Diekema, *supra* note 4, at 1014.

[39] *See id.*

[40] Pacific West Maternal and Child Health Distance Learning Network, *supra* note 3.

[41] *See* The "Ashley Treatment," *supra* note 5.

[42] *See* Gunther & Diekema, *supra* note 4, at 1014.

[43] *See* The "Ashley Treatment," *supra* note 5.

[44] *See* Gunther & Diekema, *supra* note 4, at 1014.

[45] *See* The "Ashley Treatment," *supra* note 5.

[46] *See* Gunther & Diekema, *supra* note 4, at 1014; The "Ashley Treatment," *supra* note 5; Alan Green, *supra* note 7 ("In girls, the signs to watch for are the development of the breasts, the growth of pubic hair or underarm hair, a change in the appearance of the external genitals, and the beginning of menstrual periods.").

[47] *See* Gunther & Diekema, *supra* note 4, at 1014.

[48] *See id.*

[49] *See id.*; *See* The "Ashley Treatment," *supra* note 5.

in particular, would be a source of discomfort they could not explain to her and would adversely affect her quality of life.[50]

Taking her parents' concerns into consideration, Ashley's doctors created a four-part treatment plan aimed at easing her parents' concerns about Ashley's future care and quality of life.[51] First, her physicians decided to administer high levels of estrogen with the hopes of attenuating Ashley's growth.[52] This treatment would occur with a series of dermapatches over a period of years.[53] Her physicians and parents also decided that in order to alleviate any menstrual discomfort, her uterus should be removed via a procedure known as a hysterectomy.[54] Additionally, during the hysterectomy, an appendectomy would also be performed to prevent any threat of appendicitis.[55] Finally, Ashley would undergo a procedure to remove her early breast buds in order to prevent the further development of her breasts.[56] Due to the unconventional and radical nature of these procedures, Ashley's case was referred to the hospital's ethics committee[57] for review and approval prior to commencement.[58]

While there is no available official record of the presentation of the treatment plan to the ethics committee, Ashley's parents and two members of the ethics committee espoused the arguments in favor of administering these procedures as a

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[50] *See* The "Ashley Treatment," *supra* note 5.

[51] *See id.*

[52] *See* Gunther & Diekema, *supra* note 4, at 1014.

[53] *See* The "Ashley Treatment," *supra* note 5.

[54] *See* Gunther & Diekema, *supra* note 4, at 1014.

[55] *See* The "Ashley Treatment," *supra* note 5.

[56] *See id.*

[57] *See* Anne-Marie Slowther, *They Can Change Clinical Practice but Need Evaluation*, BMJ TODAY, Sept. 16, 2000, http://www.bmj.com/cgi/content/full/321/7262/649.

> Clinical ethics committees in the United States typically perform one or more of three functions: (a) individual case consultations in response to requests from clinicians or occasionally from patients or their families; (b) providing ethical input into hospital policies and developing guidelines; and (c) education of health professionals within the institution. In practice, case consultation is more likely to be carried out by individual ethicists or increasingly by small multidisciplinary teams which may include ethics committee members as part of the team.

Id.

[58] *See* Gunther & Diekema, *supra* note 4, at 1014.

treatment option.[59] In justifying the need for attenuating her growth, they argued that the main benefits to the estrogen treatment were limiting Ashley's height and weight.[60] Her parents sought to maintain her small stature to facilitate her care through increased mobility, more physical interaction, and continued inclusion in family functions.[61] It was also posited that in limiting her growth potential and increasing her mobility there would be a reduction in infections commonly associated with similarly situated people; namely skin sores, pneumonia and bladder infections.[62]

Ashley's parents and doctors went on to contend that the hysterectomy was ethically appropriate because it would increase Ashley's quality of life.[63] Since Ashley's long-term prognosis was relatively stable, no one expected that she would ever have a need for her uterus since it was not foreseeable that she could ever *willingly* bear a child.[64] They went on to argue that this would also prevent pregnancy that could result from abuse.[65] They cited the risks associated with similarly situated disabled women being sexually abused, and argued for the necessity of this procedure as a measure to reduce the risk of pregnancy in the unfortunate event of a future abusive trauma.[66] Further, it was suggested that removal of Ashley's uterus would eliminate the possibility of her developing uterine cancer.[67]

Ashley's physicians also performed an appendectomy based upon the *five percent* chance of developing appendicitis in the

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[59] *See* The "Ashley Treatment," *supra* note 5; *see* Gunther & Diekema, *supra* note 4, at 1013.

[60] *See* The "Ashley Treatment," *supra* note 5.

[61] *See id.*

[62] *See id.*

[63] *See id.*

[64] *See id.*

[65] *See id.*

[66] *See* The "Ashley Treatment," *supra* note 5. This issue will be addressed in further detail in the discussion of the public debate of Ashley's Treatment, *infra* Section V.

[67] Prior to the proceeding with the ethics committee and ultimately the treatment, Ashley's parents also consulted an attorney regarding the possible legal ramifications regarding the "sterilization" of a mentally disabled person and were informed that Ashley's circumstances did not pose any violations of the law. *See* The "Ashley Treatment," *supra* note 5.

general population.[68] Her physicians posited that since this procedure would present no additional risk it would be beneficial for them to do it simultaneously with the hysterectomy.[69] The proffered justification was that in the future, since Ashley would not be able to communicate with them, she would not be able to express the pain resulting from appendicitis, therefore creating a risk of rupture before appropriate medical treatment could be sought.[70]

The final procedure that Ashley's parents requested was the removal of her breast buds to prevent her from developing breasts.[71] According to her parents, because of both her maternal and paternal lineage, there would be a strong possibility that she would develop large breasts.[72] They believed the development of breasts would impede Ashley's ability to be secured into the devices needed for her daily care.[73] Since her ability to mobilize herself is extremely limited, breasts would likely prove an obstacle to her continued comfort.[74] The family also expressed concerns about a history of fibrocystic growths and breast cancer.[75] Furthermore, in their continued effort to prevent the potential future abuse of their daughter,[76] Ashley's parents argued that the removal of Ashley's breasts would help to reduce her sexual appeal to future caregivers, consequently reducing the possibility of abuse.[77]

Ashley's treatment began with the hysterectomy, appendectomy and breast bud surgeries,[78] after which she began a

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[68] *See id.*

[69] *See id.*

[70] *See id.*

[71] *See id.*

[72] *See id.* ("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.").

[73] *See* The "Ashley Treatment," *supra* note 5.

[74] *See id.*

[75] *See id.* ("The breast bud removal has other benefits: 1—Avoiding the possibility of painful fibrocystic growth and future related surgeries. Women in Ashley's lineage have a history of fibrocystic growth. 2—Avoiding the possibility of breast cancer. Ashley has breast cancer history in her family.").

[76] *See id.*

[77] *See id.*

[78] *See id.*; *See* Gunther & Diekema, *supra* note 4, at 1014.

course of transdermal estriadiol (estrogen treatment via medicated patches).[79] At nine years old, because of the permanence of the procedures she has undergone, Ashley has been perpetually physically infantilized with the *hope* that the effects will be those *predicted* with no future adverse complications.[80] Her parents represent that throughout this treatment she experienced no adverse consequences.[81]

IV. ANALYSIS OF ASHLEY'S RIGHTS

In analyzing the appropriateness of "Ashley's Treatment," it is first necessary to determine what rights, if any, Ashley has as a mentally disabled child. In determining her rights one must view her roles in the two classes of which she is a member—her rights as a minor and her rights as a disabled person. The Fourteenth Amendment undeniably provides for each person the rights of life and liberty.[82] Ashley's status as both a minor and a disabled person greatly affect the way in which she is able to enjoy these rights. In addition to viewing Ashley's autonomy-based rights, it is equally compelling to consider the state's interest in protecting its citizenry.[83]

The review of these two separate classifications must include the affects of these medical decisions on any future rights that she may have. The autonomy-based rights identified should applied in the general context of the individual procedures sustained by Ashley, but will focus primarily on the growth attenuation therapy. In analyzing these many factors, it becomes important to address not only the effects on Ashley, but the potential effects on similarly situated individuals in the future.

A. *The Effects of Ashley's Treatment on Her Rights as a Minor*

While children have limited rights, these rights are generally subsumed by the long-recognized common law principle of "parental authority to make fundamental decisions for minor

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[79] *See* Gunther & Diekema, *supra* note 4, at 1014.

[80] *See* The "Ashley Treatment," *supra* note 5.

[81] *See id.*

[82] *See* U.S. CONST. amend. XIV, § 1.

[83] *See Cruzan*, 497 U.S. 261; McKay v. Bergstedt, 106 Nev. 808 (Nev. 1990).

children."[84] This principle is rooted in the belief that "[t]he primacy of the familial unit is a bedrock principle of law."[85] Although this is a strongly rooted principle, as previously stated, it does not grant complete and unqualified discretion to parents to make decisions for their children.[86] Parental autonomy is founded in the belief "that parents possess what a child lacks in maturity, experience, and capacity for judgment [which is] required for making life's difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children."[87] Though parents have a recognized right to raise their children as they see fit,[88] this right is not so absolute as to extinguish the child's Constitutional rights. The Fourteenth Amendment affords the rights of life, liberty and property equally amongst all persons.[89] In *Bellotti v. Baird*, the United States Supreme Court acknowledged that "[a] child, merely on account of his minority, is not beyond the protection of the Constitution." As the Court said in *In re Gault*, 387 U.S. 1, 13 (1967), "whatever may be their precise impact, neither the Fourteenth Amendment nor the Bill of Rights is for adults alone."[90] Though Ashley's status as a minor abridges her ability to freely exercise these rights, it is undeniable that she still possesses them. Thus, in assessing the appropriateness of attenuating her growth, it is imperative to balance Ashley's Fourteenth Amendment rights of personal autonomy against the Constitutionally protected right of parental autonomy.[91]

"The due process clause of the Fourteenth Amendment protects a parent's right to the custody, care and companionship of her children,"[92] thus courts have traditionally deferred to parental judgment in child rearing decisions.[93] The decision to

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[84] Newmark v. Williams, 588 A.2d 1108, 1115 (Del. 1991).

[85] *Id.*

[86] *See id.* at 1116.

[87] Parham v. J.R., 442 U.S. 584, 602 (1979).

[88] *See* Pierce v. Soc'y of Sisters, 268 U.S. 510, 535 (1925).

[89] *See* U.S. CONST. amend. XIV, § 1.

[90] Bellotti v. Baird, 443 U.S. 622, 633–634 (1979) (citing *In re* Gault, 387 U.S. 1, 13 (1967)).

[91] *See* U.S. CONST. amend. XIV, § 1.

[92] *In re* Welfare of Key, 836 P.2d 200, 205 (Wash. 1992).

[93] *See Parham*, 442 U.S. at 602.

attenuate Ashley's growth seems to be clearly within these powers. Arguably, based on her parents' constitutional right to make decisions concerning Ashley's welfare, the state cannot intervene unless this right is forfeited by neglect.[94] Ashley's parents have suggested that the growth attenuation will benefit her welfare by providing her a body that is more suited to her mental stature.[95] By providing her with this medical aid, the question of neglect turns not on her parents' willingness to seek medical treatment for Ashley, but rather the appropriateness of the radical option chosen.

The appropriateness of parental decisions regarding medical treatment options varies based on circumstance and jurisdiction. Generally, however, courts use a balancing test in determining what course of action to take.

> In some cases, especially those involving life-or-death situations or incompetent patients, the courts have recognized four countervailing interests that may involve the state as *parens patriae*: preserving life, preventing suicide, maintaining the ethical integrity of the medical profession and protecting third parties.[96]

The state possesses an interest in all its citizenry, holding a "special duty to protect its youngest and most helpless citizens."[97] The role of the state as a protector of its citizens dates back to the English Crown and the underlying doctrine of parens patriae.[98] "The state has a legitimate interest under its *parens patriae* powers in

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> The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.

Id.

[94] See *In re* Hudson, 126 P.2d 765, 778 (Wash. 1942) ("This is a plain recognition of the paramount right of parents to decide questions affecting the welfare of their children until such right is forfeited by neglect of parents to care for their child as required by both law and morals.").

[95] *See* The "Ashley Treatment," *supra* note 5 ("[S]he will retain more dignity in a body that is . . . more suited to her state of development . . . .").

[96] *In re* A.C., 573 A.2d 1235, 1246 (D.C. 1990).

[97] Newmark v. Williams, 588 A.2d 1108, 1116 (Del. 1991).

[98] DOUGLAS ABRAMS, A VERY SPECIAL PLACE IN LIFE: THE HISTORY OF JUVENILE JUSTICE IN MISSOURI (2003).

providing care to its citizens who are unable . . . to care for themselves."[99]

Ultimately, parental autonomy is circumscribed by the state's duty (in this case Washington), to ensure a child's protection. "Clearly, the State can intervene in the parent-child relationship where the health and safety of the child and the public at large are in jeopardy."[100]

> This prerogative of parens patriae is inherent in the supreme power of every state, whether that power is lodged in a royal person or in the Legislature, and has no affinity to those arbitrary powers which are sometimes exerted by irresponsible monarchs to the great detriment of the people and the destruction of their liberties. On the contrary, it is the most beneficent function, and often necessary to be exercised in the interests of humanity, and for the prevention of injury to those who cannot protect themselves.[101]

Thus, despite the argument that the decision to attenuate Ashley's growth falls under the Constitutionally protected right of parental autonomy, Ashley's Treatment must be evaluated in light of the possibility that it jeopardized her health, safety, and welfare.

The procedures Ashley underwent were not medically necessary and it could be further argued that they were not even medically appropriate. Both the medical journal that first publicized her treatment[102] and her parents' blog[103] acknowledge that these procedures were directed at improving quality of life and easing future care concerns evinced by her parents. Further, Doctors Gunther and Diekema acknowledged that "the possible adverse effects and risks are difficult to assess with certainty" in their application of estrogen therapy to Ashley.[104] Because there was no medical need for this treatment and because it was at best,

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[99] Addington v. Texas, 441 U.S. 418, 426 (1979).

[100] *Newmark*, 588 A.2d at 1116.

[101] Weber v. Doust, 146 P. 623, 624 (Wash. 1915) (citing Romney v. United States, 136 U.S. 1 (1890)).

[102] *See* Gunther & Diekema, *supra* note 4, at 1013.

[103] *See* The "Ashley Treatment," *supra* note 5.

[104] Gunther & Diekema, *supra* note 4, at 1015.

palliative in nature,[105] one could argue it unnecessarily jeopardized Ashley's health and safety.

As in *Newmark v. Teresa Williams/DCPS*, the rights and interests central to this case are those of Ashley's parents in deciding what is best for Ashley as set within the scope of Ashley's own rights of life and liberty.[106] In evaluating her rights as a minor, it cannot be overlooked that this treatment has long term repercussions, effectively extinguishing certain future rights such as procreation. While traditionally courts have given wide discretion to parents in making medical decisions for their minor children, many jurisdictions have employed a "best interests" test in assessing the possibility of parental neglect or abuse.[107] This test incorporates the gravity of the illness, a medical evaluation, the child's preference (not applicable in Ashley's case) and the risks associated with the treatment.[108]

With the exception of Ashley's developmental disability, she was healthy when she began undergoing these procedures. There is no evidence that this treatment was necessary. Rather the decision was based on a compelling argument by Ashley's parents and doctors regarding her future care, and a laundry list of possible future health conditions.[109] While the motives of her family regarding her future health and care may be genuine, this treatment has the potential to shape future medical and social norms regarding similarly situated minors and thus should not be judged solely on the projected long-term impacts to Ashley.[110]

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[105] *See* Gunther & Diekema, *supra* note 4, at 1014 ("We believe that foreshortening growth in these children could result in a positive benefit in the quality of life for both child and caregiver, and we propose that in situations in which parents request such an intervention, it is both medically feasible and ethically defensible.").

[106] Newmark v. Williams, 588 A.2d 1108, 1116 (Del. 1991).

[107] *In re* Eric B., 189 Cal. App. 3d 996 (Cal. 1987); *Key*, 836 P.2d at 206 ("To achieve that balance, Washington courts apply a 3-prong test. The three factors the court considers are: (1) parents' interests; (2) the risk of error created by the State's chosen procedure; and (3) the State's interest."); *see also Parham*, 442 U.S. at 599–600 (applying the same 3-part test).

[108] *See Eric B.*, 189 Cal. App. 3d at 1005.

[109] *See* The "Ashley Treatment," *supra* note 5.

[110] *See* Lee & Howell, *supra* note 20, at 1038.

> As we continue to explore the powers of science for modifying height for both boys and girls, we should keep in mind historical examples such as estrogen treatment for tall girls. These examples should help us to realize that scientific advances are always applied within a specific social context,

B. *The Effects Ashley's Treatment Had on Her Rights as a Disabled Individual*

The rights of disabled Americans have increased exponentially throughout the twentieth century.[111] During the beginning of the twentieth century the eugenics movement, discussed in further detail below, gave rise to the mentality that society would be better off if it were free from those considered to be less desirable; namely the disabled and those convicted of crimes.[112] This movement was driven by the belief that disabilities and the propensity for criminal behavior could be eliminated through sterilization. Further, it was believed was that these qualities would not be passed on if these individuals were prevented from procreating.[113] Though this movement gained a large following, it lost its steam after World War II.[114]

The attenuation of Ashley's growth presents an especially complex problem following the tremendous advances in civil rights for disabled individuals in the twentieth century. It is important to determine whether Ashley's parents or physicians violated her rights as a disabled person by facilitating the attenuation of her growth absent medical necessity.[115] Since Ashley is the first documented case of attenuating the growth of a mentally disabled person, it is beneficial to first contextualize the

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> and within that context, idealized gender relations may be as important as scientific studies in determining what we will do as practicing clinicians.

Id.

[111] *See* RUTH COLKER & ADAM A MILANI, THE LAW OF DISABILITY DISCRIMINATION (5th ed., 2005).

[112] *See* REILLY, *supra* note 1, at 31.

[113] *See id.* at 30–40.

[114] *See id.* at 68.

[115] H-320.953 Definitions of "Screening" and "Medical Necessity," http://www.ama-assn.org/apps/pf_new/pf_online?f_n=browse&doc=policyfiles/HnE/H-320.953.HTM.

> Our AMA defines medical necessity as: Heath care services or products that a prudent physician would provide to a patient for the purpose of preventing, diagnosing or treating an illness, injury, disease or its symptoms in a manner that is: (a) in accordance with generally accepted standards of medical practice; (b) Clinically appropriate in terms of type, frequency, extent, site, and duration; and (c) not primarily for the economic benefit of health plans and purchasers or for the convenience of the patient, treating physician, or other heath care provider.

Id. (emphasis added).

situation by comparing it to the historical trend of involuntary sterilization of mentally disabled individuals. The appropriate legal standard, developed as a response to involuntary sterilization, must then be applied to Ashley's Treatment to ensure the protection of the rights of similarly situated disabled individuals.

C. *The Legal Standard*

American society has a long history of discrimination against disabled individuals.[116] Throughout the beginning of the twentieth century it was believed that societal problems were the result of the behavior of "degenerates."[117] Eugenic sterilization was seen as a solution to this problem and became a relatively common practice.[118] Eugenic sterilization is a term denoting the practice of sterilizing "a person who is either mentally ill or mentally defective and will either severely handicap any future offspring through heredity or is unable to properly care for a child."[119] The eugenics movement was based on the principle that natural equality does not exist and that medical intervention was necessary to eliminate the "degenerates" of society.[120] The ideology of the eugenics movement is evinced in the United States Supreme Court decision *Buck v. Bell.*[121] *Buck*, which remains good law today, concerned a Virginia law permitting the sterilization of institutionalized patients.[122] A disabled woman brought an action seeking to enjoin this practice, based on a contended violation of her Fourteenth Amendment rights of due process and equal protection of the law; specifically relating to her bodily integrity.[123] In upholding the Virginia statute, Justice Holmes writing for the majority stated, "[i]t is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their

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[116] *See id.* at 30–40.

[117] *Id.*

[118] *Id.*

[119] *See* National Center for Biotechnology Information Website, Eugenic Sterilization, http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12332119&dopt=Abstract (last visited Nov. 7, 2007).

[120] REILLY, *supra* note 1, at 31.

[121] 274 U.S. 200 (1927).

[122] *See id.* at 205–06.

[123] *See id.*

imbecility, society can prevent those who are manifestly unfit from continuing their kind."[124] The eugenic philosophy manifests itself in this decision and, although not practiced as often anymore, it continues to exist to some extent in contemporary society.[125]

Even today, parents of disabled children are permitted to request that their children be sterilized.[126] The Washington State Supreme Court established "standards of sterilization" in its 1980 opinion *In re Hayes.*[127] In this decision, the court recognizes that though *Buck*[128] is still good law, the underlying principals of eugenic sterilization are no longer valid.[129] The Court noted that "[s]terilization touches upon the individual's right of privacy and the fundamental right to procreate."[130] The standard required for sterilization of a mentally disabled individual to be judicially approved was set forth in this decision.[131]

> The decision can only be made in a superior court proceeding in which (1) the incompetent individual is represented by a disinterested guardian ad litem, (2) the court has received independent advice based upon a comprehensive medical, psychological, and social evaluation of the individual, and (3) to the greatest extent possible, the court has elicited and taken into account the view of the incompetent individual.[132]

These are the requisite elements for a case to receive judicial approval for sterilization. In satisfying these elements, the court must look to the current and expected future competency of the ward.[133] It must also be proved by "clear, cogent and convincing evidence that there is a need" and there is no other less invasive treatment option available.[134]

Sterilization is highly analogous to growth attenuation for legal comparative purposes. Both procedures require the

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[124] *Id.* at 207.

[125] *See* REILLY, *supra* note 1.

[126] *See In re* Guardianship of Hayes, 608 P.2d 635, 639 (Wash. 1980).

[127] *Id.*

[128] *See* Buck v. Bell, 274 U.S. 200 (1927).

[129] *Hayes*, 608 P.2d at 639.

[130] *Id.*

[131] *Id.* at 640.

[132] *See id.* at 641.

[133] *See id.*

[134] *Id.*

impediment of natural bodily functions and raise issues over the protection of bodily integrity. There is a recognized fundamental right of privacy protected by the Constitution.[135] It must be questioned whether growth attenuation invades this right so as to require guidelines similar to those set forth for sterilization. Like sterilization, the same concerns are raised in performing an unalterable procedure on a mentally disabled individual. "It is an unalterable procedure with serious effects on the lives of the mentally retarded person and those upon whom he or she may depend . . . [t]herefore, it should be undertaken only after careful consideration of all relevant factors."[136]

D. *Applying the Legal Standard*

Since Ashley is the first reported case of growth attenuation being used as a treatment option on a mentally disabled person, it is critical to consider the guidelines set forth by the judiciary in the sterilization context to ensure the protection of her Constitutional rights, namely her health and welfare. The effects of this treatment on young children are largely untested and unknown.[137] Furthermore, the effects of this treatment on someone with severe mental disabilities may be different than on someone without such disabilities.[138] Based on the historical context of the rights of the disabled, two issues come into play: the appropriateness of shortening people in a social context, and the need for the highest scrutiny and safeguards when applying such a radical treatment to children with severe mental disabilities.[139]

Using the review standard set forth in *Hayes*, in Ashley's case it becomes alarmingly clear that the purpose of her treatment was not to rectify any existing medical problem, nor was it performed

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[135] *See Hayes*, 608 P.2d at 639 ("Sterilization touches upon the individual's right of privacy and the fundamental right to procreate.").

[136] *Id.*

[137] *See* Gunther & Diekema, *supra* note 4, at 1015 ("Because we have no direct experience with high-dose-estrogen treatment in young children, the possible adverse effects and risks are difficult to asses with certainty.").

[138] *See* Brosco & Feudtner, *supra* note 24, at 1077 ("While there are data that high-dose estrogen treatment will make extremely tall-for-age (but otherwise normal) girls shorter adults, this effect may be different in the population of children with severe disabilities. More needs to be known.").

[139] *See id.* at 1078.

with any certainty of results.[140] Following the precedent established by the Washington Supreme Court in *Hayes*,[141] it does not appear that Ashley's case satisfies the first requirement that the disabled individual be represented by a guardian ad litem. While it is true that her parents were the primary advocates for her treatment, the ethics committee, acting as an independent party, ultimately judged the appropriateness of the treatment.[142] This does not satisfy the first requirement as set forth in *Hayes* because the ethics committee is not the equivalent of a guardian ad litem.[143] There is no evidence in this case that any Washington State Court approved the ethics board to represent the interests of Ashley. In fact, in May of 2007, the Washington Protection & Advocacy System, issued a report finding that the actions taken by the hospital with regard to both Ashley's sterilization and growth attenuation without a court order "was conducted in violation of Washington State law, resulting in violation of Ashley's constitutional and common law rights."[144]

Even assuming that a liberal interpretation was adopted to accept the judgment of the ethics committee, the burden of proof requiring "clear, cogent, and convincing evidence" was not met regarding the *need* for growth attenuation.[145] Ashley's treatment was not based on a premise of medical need. This seems to be in direct conflict with the interests of the state and the guidelines set forth by the Washington Supreme Court.[146]

Despite the lack of medical need, it is compelling to note that other courts acknowledge the potential "quality of life" benefits of the treatment at hand when evaluating extraordinary medical decisions.[147] Though estrogen therapy has reduced Ashley's

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[140] *See* The "Ashley Treatment," *supra* note 5.

[141] *See Hayes*, 608 P.2d 635.

[142] *See* Gunther & Diekema, *supra* note 4, at 1014.

[143] BLACK'S LAW DICTIONARY 313 (2nd Pocket ed. 2001) ("A guardian, usu. a lawyer, appointed by the court to appear in a lawsuit on behalf of an incompetent or minor party.").

[144] DAVID A. CARLSON & DEBORAH A. DORFMAN, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 1 (May 8, 2007), *available at* http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment.pdf.

[145] *Hayes*, 608 P.2d at 641.

[146] *See id.*

[147] McKay v. Bergstedt, 106 Nev. 808, 813–14 (Nev. 1990).

projected overall growth potential, the quality of life benefits asserted seem to be outweighed by the benefits this procedure provides to her caretakers.[148] The social context of shortening a mentally disabled person for benefits that are not proven becomes questionable at best. Social influences have previously driven the use of estrogen therapy for cosmetic reasons.[149] Yet this use is distinguishable because those being treated for cosmetic purposes were cognizant of the procedure and willingly chose to conform.

Offering growth attenuation as a treatment option for mentally disabled individuals, without setting controlled guidelines, can potentially result in the degradation of these individuals by creating social and medical norms that all mentally disabled should be shorter and lighter to accommodate the convenience of their caregivers.[150] Therefore, in order to protect the Constitutional rights of these individuals, it is imperative that guidelines are established by state legislatures to control the use of estrogen therapy as a treatment option for the mentally disabled. As seen in the report issued by Washington Protection & Advocacy System, necessary steps have already been taken to ensure that Children's Hospital (Ashley's hospital) implement policies and procedures to prevent "Ashley's Treatment" from being implemented without a court order.[151]

V. THE PUBLIC DEBATE REGARDING ASHLEY'S TREATMENT

Ashley's Treatment has provoked a series of ethical debates around the globe. Having a disabled child comes with a multitude of social, economic, and emotional responsibilities and pressures.[152] The stress experienced by families pervades life and

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[148] *See* The "Ashley Treatment," *supra* note 5 ("We tried hard and found it impossible to find qualified, trustworthy, and affordable care providers. The main benefit of the height and weight reduction is that Ashley can be moved considerably more often . . . .").

[149] *See* Lee & Howell, *supra* note 20, at 1037.

[150] *See* CARLSON & DORFMAN, *supra* note 144 ("The implementation of the "Ashley Treatment" also raises discrimination issues because, if not for the individual's developmental disabilities, the interventions would not be sought. Such discrimination against individuals because of their disabilities is expressly forbidden by state and federal law.").

[151] *See id.*

[152] *See id.*

the quality of care administered to the disabled child.[153] It is therefore important to acknowledge these pressures in understanding the justifications for Ashley's Treatment.

In a recent interview with CNN, Doctor Douglas Diekema, who first publicized Ashley's Treatment in his article "Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma," answered some questions about the decision of the ethics board.[154] Although he offered some insight[155] into the mindset of the board, his answers did not quell the rising debate. During this interview, Doctor Diekema stated that "[o]ne of the difficult things about being a physician is sometimes you don't know for sure. We strive to do no harm, but that has to be balanced against what good you might do for a patient . . . ."[156]

In an interview with Time, Inc., Doctor Daniel Gunther, who co-wrote the article with Doctor Diekema in the *Archives of Pediatric & Adolescent Medicine*, further defended the decision to administer this treatment stating, "[t]o those who say she has a right to develop and grow . . . [I say] Ashley has no concept of these things."[157] In her criticism of this contention, author Nancy Gibbs states that "he is talking as a scientist; the philosopher uses different tools. Just because autonomy doesn't show up on an X-ray doesn't mean it can't be harmed by a scalpel. And if rights are

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[153] *See id.*

[154] *See* Interview by Amy Burkholder with Dr. Douglas Diekema, *Ethicist in Ashley Case Answers Questions*, CNN.COM, Jan. 11, 2007, http://www.cnn.com/2007/HEALTH/01/11/ashley.ethicist/index.html.

[155] *See id.*

> There were two main aspects to the parents' requests. We looked at whether we should permit growth attenuation to occur and whether we should permit a hysterectomy. The first issue was, do these things have the potential to improve this little girl's quality of life? Will they make her life better? And the second issue was, what's the potential for harm here and is it significant [enough] that even with the prospect of some benefit we shouldn't allow it to move forward? It was the consensus of the committee this did in fact actually have potential to improve her life significantly and there was very little actual harm.

Id.

[156] *See id.*

[157] *See* Nancy Gibbs, *Pillow Angel Ethics*, TIME, Jan. 22, 2007.

inalienable, they exist whether the patient is aware of them or not."[158]

Acknowledging Doctors Gunther and Diekema's position, Doctors Jeffrey Brosco and Chris Feudtner expressed, in an editorial response to the original article, four primary concerns[159]—the need for further research on the effects in young children, the social impacts, the legal civil rights interests and whether the ends justify the means for such extraordinary treatment.[160] They argued that no studies had been performed to evaluate the effects of estrogen treatment on such young children.[161] They also expressed their concerns about the social and legal implications of administering this treatment to disabled children. In attenuating the growth of these individuals, the doctors stated their concern in trending a social and medical norm resulting in the small stature of all similarly situated individuals. While they ultimately disagree with Doctors Gunther and Diekema's suggestion that estrogen therapy be used as a treatment option for the mentally disabled,[162] they commend them for starting the debate.[163]

Other commentators focus their criticism on the fact that Ashley was in perfect physical health when she underwent this therapy. Doctor Tom Shakespeare, of the University of Newcastle, stated for the *London Times* that these procedures are invasive, radical, and "have not fixed anything. What they have 'corrected,' as it were, did not necessarily need fixing."[164] His concern also came from viewing Ashley's parents' blog in which they referred to her as their "pillow angel"[165] and he speculates that they seek to

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[158] *See id.*

[159] *See* Brosco & Feudtner, *supra* note 24, at 1077–78.

[160] *See id.*

[161] *See id.*

[162] *See* Gunther & Diekema, *supra* note 4, at 1014 ("We believe that the foreshortening growth in these children could result in a positive benefit in the quality of life for both child and caregiver, and we propose that in situations in which parents request such an intervention, it is both medically feasible and ethically defensible.").

[163] *See id.* at 1078. ("Although we believe that attempts to attenuate growth are ill advised, we applaud Gunther and Diekema for publishing this case report.").

[164] *See Why We Had To Do It*, THE TIMES (London), Jan. 5, 2007, at 4.

[165] *See id.*

perpetually infantilize her by avoiding natural physical growth and aging.[166]

CNN reported a response to the parents' blog from a young man with cerebral palsy.[167] He strongly condemned Ashley's parents stating, "Ashley's parents have committed the ultimate betrayal . . .[by] treat[ing] their daughter as less than human, not worthy of dignity . . . . What strikes me about 'the Ashley treatment' and has brought me to tears is that the very people in all of society whom this child should trust have betrayed her."[168]

While numerous people may disagree with Ashley's Treatment, there are also those who praise her parents.[169] Ashley's parents have posted on their blog numerous supportive comments from others.[170] Many commended them on their efforts to ensure Ashley's comfort.[171] Her parents' blog lists numerous testimonials from others caring for disabled family members and comments from those who generally support Ashley's growth attenuation as a treatment option.[172] Despite their own justifications and those of Doctors Gunther and Diekema, it is likely that neither the public at large nor the medical community will reach a consensus on their own accord anytime soon. Thus it is important to create standards for the protection of disabled individuals.

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[166] *See id.*

[167] *See* Elizabeth Cohen, *Disability Community Decries 'Ashley Treatment'*, CNN.COM, Jan. 12, 2007, http://www.cnn.com/2007/HEALTH/01/11/ashley.outcry/index.html.

[168] *Id.*

[169] *See id.*

[170] *See* The "Ashley Treatment," *supra* note 5.

[171] *See id.*

> I have read the story of Ashley on Fox News and then your blog . . . more than once . . . I want to write to tell you how incredibly impressed I am with you and your doctors. To make such difficult decisions about placing a loved child under anesthesia and surgeries must be hard, but to be able to plan for Ashley's future life and care is incredibly impressive. I applaud you and the doctors again for making such brilliant and forward thinking choices. I am hopeful that others will read about this and be able to "take a page" out of your story and perhaps help another beautiful human being benefit.

Id.

[172] *See id.*

VI. CONCLUSION

There is currently no uniform system for assessing the appropriateness of radical medical treatments. Most ethical committees in hospitals consist of a completely self-governed interdisciplinary body. Though there is some judicial guidance relating to some specific situations, generally, making the decision to allow an extraordinary medical treatment is charting into an unknown area.[173] Further, in validating estrogen therapy as a treatment option for mentally disabled children, there is a general assumption of altruistic motives on behalf of all caregivers to act in the best interest of the disabled child. However, the District of Columbia Court of Appeals recognized that:

> The court should be mindful, however, that while in the majority of cases family members will have the best interests of the patient in mind, sometimes family members will rely on their own judgments or predilections rather than serving as conduits for expressing the patient's wishes.[174]

Even though this treatment may hold some value for some mentally disabled individuals, due to its irreversible nature, it should not be permitted without conforming to legislative standards aimed at protecting the constitutional liberties of the individual. In the absence of these standards, some courts recognize the need for judicial intervention when there is evidence of disagreement or of wrongful motives.[175] The Washington Protection & Advocacy System, has seen the need for intervention in order to protect disabled minors when "Ashley's Treatment" is proposed as an option.[176]

Indeed, it is compelling to consider the long-term problems with establishing this precedent. Though the possibility for abuse of this treatment has been acknowledged, the issue of abuse outside the family or the doctor-patient context has yet to be

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[173] *See In re* Guardianship of Hayes, 608 P.2d 635, 639 (Wash. 1980); Buck v. Bell, 274 U.S. 200 (1927).

[174] *In re* A.C., 573 A.2d 1235, 1250 (D.C. 1990).

[175] *See* John F. Kennedy Mem'l Hosp. v. Bludworth, 452 So. 2d 921, 926–927 (Fla. 1984) ("Disagreement among the physicians or family members or evidence of wrongful motives or malpractice may require judicial intervention upon the filing of an appropriate petition.").

[176] *See* CARLSON & DORFMAN, *supra* note 144.

addressed, specifically with regard to insurance costs. With the rising costs of healthcare, growth attenuation of the disabled offers the potential benefit of reducing the long-term costs of care and treatment for both the family and the insurer, whether government or private. In maintaining a small stature, one is eliminating the need for harnesses, bigger wheelchairs and other devices that would normally need to be replaced as the disabled person physically outgrows them. Without a defined standard of qualification or further evaluation of the treatment as a therapeutic option, it leaves open the threat of abuse by insurers looking to cut costs.

It is unlikely that the debate over this issue will result in an amicable solution anytime soon. Yet, Ashley's case will undoubtedly begin the necessary discussions aimed at protecting the most vulnerable members of society in any future administration of similar treatments. There is no doubt that the legislature itself would be incapable of regulating this as closely as it should be. Thus it is necessary for them to create an independent agency to establish rules and monitor behavior in this arena. The need to protect those that cannot protect themselves is a governmental responsibility.[177] The Washington Protection & Advocacy System, is a non-profit organization that has taken upon itself the role to protect Washington citizens with disabilities.[178] While other states may have similar organizations to protect disabled citizens, it should be required that they take a more active role in establishing guidelines when "Ashley's Treatment" becomes an option.

Additionally, as recognized by the Washington Protection & Advocacy System, judicial review is necessary before Ashley's Treatment should be administered.[179]

> As acknowledged in *Hayes* and *K.M.*, it cannot be assumed that parents, guardians, or doctors have identical interests as the child for whom the sterilization is sought. By including the required court review with full due process protections as

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[177] *See* Abrams, *supra* note 98 (referring to the history of and responsibilities associated with *parens patriae*).

[178] *See* "Ashley Treatment" Investigation, http://www.disabilityrightswa.org /news-1/ashley-treatment-investigation (last visited May 12, 2008).

[179] *See* CARLSON & DORFMAN, *supra* note 144.

> required by *Hayes* and *K.M.*, and approval for the 'Ashley's Treatment' as a whole in hospital policies, hospitals and doctors can ensure that their patients have someone advocating for the child and can hopefully avoid unintentionally violating their patients' civil rights.[180]

Therefore, it is with the utmost urgency that the administration of "Ashley's Treatment" and similar programs be prevented until further action is taken to protect the interests and liberties of those potentially affected. There is little doubt that the debate over whether or not "Ashley's Treatment" is ethical will continue. "Guaranteeing procedural due process for all people facing the 'Ashley Treatment' or other growth-limiting medical interventions will not . . . answer the question of whether the 'Ashley Treatment' *should* be done." Guaranteeing these procedural due process rights however is a step in the right direction.

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[180] *Id.*