

11-27-2013

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Recommended Citation

Mills, Meryl Eschen. "The Legal and Moral Implications of Growth Attenuation." *Health Law & Policy* 1, no. 2 (2007): 12-23.

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THE LEGAL AND MORAL IMPLICATIONS OF GROWTH ATTENUATION

By Meryl Eschen Mills*

I. Introduction

One of the goals of the *Healthy People 2010* initiative, advanced by the U.S. Department of Health and Human Services is to “[r]educe the number of people with disabilities in congregate care facilities” to zero by the year 2010.¹ According to the American Academy of Pediatrics Committee Section on Children with Disabilities, “[m]ost parents desire to raise their children with special health care needs at home.”² However, caring for a child with profound developmental disabilities can be particularly difficult as the child matures into adulthood. A child’s continued physical growth may impose significant limitations on a parent’s ability to care for the child.

As a result, some doctors have proposed a controversial method of “treatment,” designed to mitigate particular challenges that caregivers face due to the continued growth of a child with severe disabilities. This treatment, termed “growth-attenuation therapy” consists of using treatments of high-dose estrogen at an early age in order to stimulate growth of the epiphyseal growth plates, which in turn permanently attenuates physical size.³ “[A]chieving permanent growth attenuation while the child is still young and of manageable size would remove one of the major obstacles to family care and might extend the time that parents with the ability, resources, and inclination to care for their child at home might be able to do so.”⁴

Not surprisingly, this controversial method of intervention has caused considerable debate both in the United States and abroad. Ashley, a nine-year-old girl with severe cognitive and developmental disabilities is at the center of this controversy. At the request of Ashley’s parents, doctors have attenuated Ashley’s growth, and performed other procedures, believing that such measures will provide a better “adult quality of life” for their daughter.⁵

This article explores the legal and ethical implications of Ashley’s “treatment.” Although there is no explicit legal prohibition on growth attenuation, the fact that doctors are *capable* of performing a particular intervention does not necessarily mean they *should*.

This article juxtaposes the moral question at issue with an analysis of the legal rights available to the parents and child, respectively.

II. Background

Ashley is a nine-year-old girl who was born with static encephalopathy, a medical condition resulting in severe developmental and cognitive deficiencies.⁶ Ashley requires assistance moving her body, is fed through a gastrostomy tube,⁷ and her mental development has remained and will likely continue to remain that of an infant.⁸ Her parents call her their “Pillow Angel, since she is so sweet and stays right where [they] place her – usually on a pillow.”⁹

When Ashley was six-years-old, she started showing signs of puberty.¹⁰ Ashley was growing quickly and had already started developing breasts.¹¹ Ashley’s early pubertal development prompted fear in her parents: Ashley’s “continued growth eventually would make it untenable for them to care for their daughter at home, despite their strong desire to do so.”¹² Ashley’s parents expressed concern over one day having to place her “in the hands of strangers.”¹³ They were also concerned with the potential complications of puberty, including what would happen if their daughter started menstruating.¹⁴

To “significantly elevate Ashley’s adult quality of life,” her parents and doctors developed a plan for Ashley involving growth attenuation, a hysterectomy, and breast bud removal.¹⁵ The parents termed this collective set of medical procedures, “Ashley’s Treatment.”¹⁶ The purpose of the hysterectomy was to “prevent the discomfort, pain, cramps and bleeding that are so commonly associated with the menstrual cycle.”¹⁷ Ashley’s parents noted that additional benefits included “avoiding the possibility of pregnancy” in case Ashley is abused, eliminating the risk of uterine cancer,¹⁸ and further claimed that she “has no need [for her uterus] . . . since she will not be bearing children.”¹⁹ Although doctors removed Ashley’s uterus, they did not remove her ovaries in order to ensure that she will maintain “her hormonal cycle and the generation of her natural hormones.”²⁰ “This onetime [sic] procedure eliminates the complications of menses,” sparing Ashley and her parents “the expense, pain, and inconvenience of a lifetime of hormone injections.”²¹

Ashley’s parents based their decision to remove Ashley’s breast buds on family history since large breasts

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run in Ashley's mother's family.²² Ashley's parents contend that large breasts would be uncomfortable for Ashley, and may impede their ability to safely secure Ashley in her wheelchair.²³ Incidental benefits include eliminating the risk of breast cancer and fibrocystic growths, both of which also run in Ashley's family.²⁴ Ashley's parents were further concerned that large breasts might "sexualize" her towards her potential caregivers, especially if touched accidentally during Ashley's care.

The onset of puberty typically causes a child to grow significantly. Doctors have found that premature exposure to sex steroids, such as estrogen, can stunt final adult height by inducing the quick maturation of growth plates.²⁵ The earlier a child is exposed to such steroids, the more significant the growth attenuation will be.²⁶ Since Ashley first underwent such treatment when she was merely six-years-old, her height will likely never exceed four feet, five inches, and her weight will remain approximately 75 pounds.²⁷

This is not the first time such treatment has been used to stunt a child's growth. The first reported use of high-dose estrogen as a means to attenuate growth was reported in 1956.²⁸ Such treatment was often used on girls who were considered "too tall" before reaching puberty to minimize additional growth.²⁹ While doctors still use growth attenuation as a treatment option today, it is far less common, as the stigma previously associated with women of tall stature has decreased significantly.³⁰

Potential side effects of the treatment are somewhat uncertain since doctors have limited experience with the use of growth attenuation in young children.³¹ Doctors believe the side effects associated with this treatment may be significant, causing early onset of breast development and uterine bleeding.³² The potential for these side effects to develop in the future contributed to the rationale for removing Ashley's uterus and breast buds.

III. LEGAL IMPLICATIONS

Courts generally afford substantial deference to parents making "important decisions for their children."³³ State and federal law grants parents decision-making authority with regard to choices involving children's health care.³⁴ While there is a presumption in favor of a parent's autonomy over health care decisions, courts may overrule a parent's wishes in certain circumstances. When a parent chooses to withhold certain treatment for reasons unrelated to the well-being of the child, for example, a court may order treatment for the child if it is not highly invasive and if it is likely to have significant health benefits.³⁵ Where the treatment's

success is lower or substantially uncertain, courts may be less likely to overrule the parents' or child's wishes.³⁶

Some states, such as Washington, where Ashley and her family currently reside, require court approval of certain health care decisions before they are performed.³⁷ These health care decisions include those that are "highly invasive and irreversible," such as involuntary sterilization.³⁸

Washington law is clear about involuntary sterilization. In *In re Guardianship of Hayes*, the Washington Supreme Court considered whether a mother could consent to the sterilization of her child, who had severe mental retardation.³⁹ The court held that "in any proceedings to determine whether an order for sterilization should issue, the retarded person must be represented, as here, by a disinterested guardian *ad litem*."⁴⁰ The court found that a guardian is necessary in such cases because "unlike the situation of a normal and necessary medical procedure, in the question of sterilization the interests of the parents of a retarded person cannot be presumed to be identical to those of the child."⁴¹ Thus, "[t]here is a heavy presumption against sterilization of an individual incapable of informed consent...[t]his burden will be even harder to overcome in the case of a minor incompetent."⁴²

Ashley's hysterectomy rendered her sterile. Because her parents did not seek a court order or request the appointment of a guardian *ad litem* before consenting to the hysterectomy, the Washington Protection and Advocacy System found that this aspect of "Ashley's Treatment" violated both the United States Constitution and Washington state law.⁴³ Whether other procedures associated with "Ashley's Treatment," also violated Washington law remains unclear. The Washington Protection and Advocacy System argues that the removal of Ashley's breast buds, the hormone therapy, and the other procedures associated with Ashley's treatment also violate her constitutional rights because they are "highly invasive and irreversible, particularly when implemented together."⁴⁴

Interestingly, all arguments supporting and opposing Ashley's treatment, including of the Washington Protection and Advocacy System, seem to assume that the array of procedures actually constitutes medical "treatment" protected by constitutional and common law. The American Association on Intellectual and Developmental Disabilities (AAIDD) points out that the doctors exploring growth attenuation as a treatment for children with Ashley's condition "seemed to implicitly accept the idea that growth attenuation is in fact a type of therapy Given that therapy is intended to

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address a condition of a patient, the target in this case would have to be the growth and maturation expected as a consequence of Ashley’s normal development.”⁴⁵

A preliminary review of the case law reveals no judicial definitions of “medical treatment.” Courts frequently pass judgment on the appropriateness of parents’ medical treatment decisions on behalf of their children, particularly when such decisions are not religiously motivated. For example, in *In re Cicero*, the Supreme Court of New York considered whether to appoint a guardian for an infant born with spina bifida because the infant’s parents refused to consent to surgery to help repair the infant’s condition.⁴⁶ If treated, the court found that the infant’s “extremity deficits will, hopefully, be only at the leg level below the ankles. Additionally, she will lack sphincter control of the bladder and anus; but modern medicine and surgery can ameliorate these conditions too. She should be able to walk with short leg braces and hopefully have a ‘normal’ intellectual development.”⁴⁷

The court granted the appointment of a guardian, reasoning:

This is not a case where the court is asked to preserve an existence which cannot be a life. What is asked is that a child born with handicaps be given a reasonable opportunity to live, to grow and hopefully to surmount those handicaps. If the power to make that choice is vested in the court, there can be no doubt as to what the choice must be.⁴⁸ The court distinguished between “hopeless” lives and the case at bar, without defining what a “hopeless” life entailed. The court continued:

There is a hint in this proceeding of a philosophy that newborn, ‘hopeless’ lives should be permitted to expire without an effort to save those lives. Fortunately, the medical evidence here is such that we do not confront a ‘hopeless’ life. As Justice Asch has pointed out [citation omitted] ‘(t)here is a strident cry in America to terminate the lives of *other* people—deemed physically or mentally defective.’

This court was not constituted to heed that cry. Rather, to paraphrase Justice Asch [citation omitted] it is our function to secure to each his opportunity for ‘life, liberty and the pursuit of happiness.’⁴⁹

A case before the Supreme Court of Massachusetts, however, provides an example of a “hopeless life.”⁵⁰ In *In re Custody of a Minor*, the court affirmed a “no code” order for a four-and-one-half-month-old infant suffering from cyanotic heart disease, a condition without a cure, which would cause fatal complications for the infant within a year regardless of whether the hospital administered treatment.⁵¹ The court reasoned that “[a] ‘full code’ order would involve a substantial degree of bodily invasion, accompanied by discomfort and pain, and would do nothing but prolong the child’s ‘agony and suffering.’”⁵²

In deciding whether to intervene with parents’ medical decisions on behalf of their children, courts seem to draw the line at whether a child’s situation is hopeless and death is imminent regardless of treatment, or whether treatment might help the child. In Ashley’s case, her condition does not pose an imminent threat to her health. Therefore, one must question whether measures taken allegedly to improve Ashley’s quality of life should also be subject to judicial intervention.

The Access to Medical Treatment Act, a recently proposed bill, would “permit an individual to be treated by a health care practitioner with any method of medical treatment such individual requests, and for other purposes.”⁵³ While it is unclear whether the bill addresses treatment for children whose parents request medical treatment on their behalf,⁵⁴ it defines “medical treatment” as “any food, drug, device, or procedure that is used and intended as a cure, mitigation, treatment, or prevention of disease or a health condition.”⁵⁵

In Ashley’s case, the treatment regimen will not *cure* her underlying condition. Whether Ashley’s full-term growth would constitute a “disease” or “health condition” is also unclear. Ashley’s treatment may *mitigate* her condition in the sense of making her more comfortable. For example, Ashley’s doctors argue that “[a] child who is easier to move will in all likelihood be moved more frequently. Being easier to move

means more stimulation, fewer medical complications, and more social interactions.”⁵⁶

Courts also consider the mental capacity of the child when evaluating a parent’s medical treatment decision. For example, in the case of the child with spina bifida, the court carefully pointed out that the child would likely have “normal” intellectual development. While Ashley’s condition does not pose an imminent threat to her health, her mental development will not be “normal.” One should consider how, if at all, Ashley’s mental capacity should influence a court’s decision as to whether to allow her parents’ proposed treatment.

Courts may use mental capacity as criteria in assessing whether certain medical decisions are appropriate. For example, courts have allowed caregivers to terminate a child’s life in cases where the child has minimal brain function, such as a child in a persistent vegetative state.⁵⁷ Therefore, it becomes important to determine where courts “draw the line” regarding the appropriateness of certain medical procedures given the mental capacity of the patient.

In balancing whether to approve a medical procedure for a minor, a court may also look at the minor’s health care wishes. In Ashley’s case, however, her wishes are not ascertainable due to her cognitive disabilities. Therefore, her parents will be responsible for making all of her health care decisions. Where a parent makes a health care decision for a child whose health care wishes are not ascertainable, the court may use one of two standards to determine whether the parents’ wishes should be upheld. These standards are: (1) the “substituted judgment” standard;⁵⁸ and (2) the “best interest” standard. For example, the law allows parents of a patient in a persistent vegetative state, or of an anencephalic child, to make decisions regarding treatment options. In the case of a patient in a persistent vegetative state, the law allows the patient’s proxy to make choices for the patient, based on what the patient likely would have wanted. This type of proxy decision making is called “substituted judgment.”⁵⁹ In the case of an anencephalic child whose wishes could not be known, the law allows the proxy to make decisions based on the best interests of the patient.⁶⁰

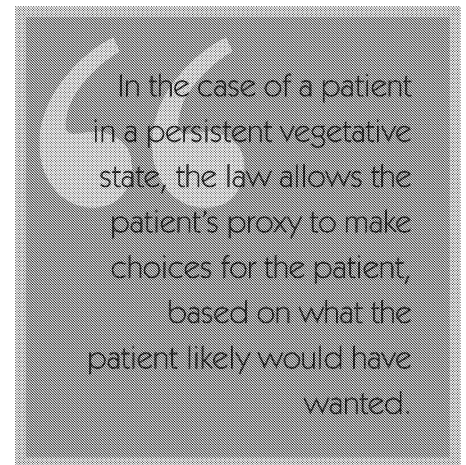
Courts have applied the substituted judgment standard in cases involving patients with profound mental retardation. In *Superintendent of Belchertown State School v. Saikewicz*, the Supreme Court of Massachusetts applied the substituted judgment standard in affirming the lower court’s decision to withhold chemotherapy for Mr. Saikewicz, a 67-year-old man with profound mental retardation.⁶¹ Though today such a measurement is considered somewhat misleading,⁶² the court found that the 67-year-old man had “a mental age of approximately two years and eight months,” and an “I.Q. of ten.”⁶³

In applying the substituted judgment standard, the court looked at “the decision . . . which would be made by the incompetent person, if that person was competent”⁶⁴ In particular, the court considered several factors favoring the administration of chemotherapy, including: (1) the fact that, if given a choice, most people would likely elect to have chemotherapy in this situation; and (2) the possibility that such treatment would prolong Saikewicz’s life.⁶⁵ The court assumed that since this treatment is what “most people” would have wanted, it must be what Saikewicz likely would have wanted had he been competent to make such a decision.

The court found six factors opposing the administration of chemotherapy, including: (1) Saikewicz’s advanced age; (2) the possible side effects of the chemotherapy; (3) the fact that the chemotherapy would not likely cause the leukemia to go into remission; (4) the fact that the chemotherapy would cause suffering; (5) Saikewicz’s inability to cooperate with the treatment, given his insufficient comprehension; and (6) Saikewicz’s potentially diminished quality of life even if the chemotherapy did work.⁶⁶ Since the factors opposing the treatment outweighed those supporting it, the court ruled to withhold the treatment.

If a court were to examine Ashley’s treatment under the substituted judgment standard, it would likely not find such treatment options preferable. Since Ashley has never been competent, a court applying the *Saikewicz* substituted judgment standard would evaluate whether Ashley would want such medical procedures if she had been competent. A six-year-old girl would most likely not want to have a hysterectomy, breast bud removal, or hormone therapy to keep her small. Ashley’s case differs from Saikewicz’s in that her treatment serves to prevent the occurrence of certain life stages *because* Ashley has mental disabilities, whereas the purpose of Saikewicz’s treatment was intended to combat his leukemia. Ashley’s parents might argue that she would prefer such treatment if it enabled her to remain a part of her family. Her parents would want a court to apply the substituted judgment analysis by asking not what a *competent* Ashley would choose in this situation, but rather, what a competent Ashley would choose if she knew she was going to be *incompetent*.

Ashley’s parents would likely fare better in a court that applied a best interest analysis. In a best interest analysis, “[t]he decision is not based on the surrogate’s view of quality of life, but ‘the value that the continuation of life has for the patient . . .’ not ‘the value that others find in the continuation of the patient’s life’”⁶⁷ In making such a decision, the court must evaluate objective, societally shared criteria. The best interests standard rests on the protection of patients’ welfare rather than on the value of self-determination. “In assessing whether a procedure or course of treatment would be in a patient’s best interests, the surrogate must take into account factors such as the relief of suffering . . . and the quality as well as the extent of life sustained.”⁶⁸



In the case of a patient in a persistent vegetative state, the law allows the patient’s proxy to make choices for the patient, based on what the patient likely would have wanted.

Potential benefits to Ashley may include greater stimulation, more social interactions with family and friends, and fewer medical complications from puberty.⁶⁹ Another potential benefit would be that “growth attenuation may offer some parents at least the opportunity to extend the time they can care for their child at home, whereas otherwise institutionalization, or foster care, might be the only alternative.”⁷⁰ Ashley’s parents argue that these benefits serve to alleviate Ashley’s suffering and improve her quality of life, both of which satisfy the criteria under a best interest analysis.

[A] court would likely need to conduct a balancing test in order to weigh the potential harms and benefits of Ashley's treatment.

Ashley's parents' argument, however, involves several assumptions. Notably, they assume that home care is objectively better than care provided at a specialized institution. They also assume that they are, in fact, correct in their predicted inability to care for Ashley in their home if she were permitted to grow to her natural size without growth attenuation treatment. Such assumptions need to be evaluated on a case-by-case basis.

As for the relief of suffering, the treatment is not without potential side effects. One possible risk of the treatment is thrombosis, a potentially fatal formation of a blood clot in an artery or vein.⁷¹ Furthermore, Ashley's doctors may not have considered the potential emotional effects that stunted growth, hysterectomy, or breast bud removal could have on Ashley. Quite possibly, such procedures could have a profound effect on Ashley. While her doctors assert that "it is unlikely that such 'infantilization' harms a person whose mental capacity will always remain that of a young child,"⁷² children, even those with severe mental disabilities, may still react to environmental stimuli. Despite her mental incapacity, Ashley may find the surgery, therapy, or side effects both physically and emotionally painful.

Ashley's doctors apparently evaluated the benefits and risks of Ashley's treatment based upon how they perceive Ashley would fit into traditional society. They argue:

Height and normal stature clearly have social value for most individuals. Being taller has been associated with enhanced social stature, greater pay, greater success in attracting a mate, and other social benefits. However, a nonambulatory, severely impaired child is not someone who will experience these benefits of tall stature and therefore will not suffer their loss if kept short. For an individual who will never be capable of holding a job, establishing a romantic relationship, or interacting as an adult, it is hard to imagine how being smaller would be socially disadvantageous.⁷³

In fact, the doctors assert that it might be advantageous for Ashley to look young and remain small because "for a person with a developmental age of an infant, smaller stature may actually constitute an advantage because others probably would be more likely to interact in ways that are more appropriate to that person's developmental age."⁷⁴

One could argue that Ashley's doctors' reasoning is right—that allowing Ashley to grow "naturally" is really not "natural" for her at all. Generally, it is presumed that physical development will be concurrent

with mental development, and thus expected that a person with the "mental capacity" of a six year old will look like a six year old. Therefore, one might justify Ashley's growth attenuation treatment by arguing that it would be unnatural for Ashley to develop to her expected normal size because her mental capacity will never be that of an adult.

Were it the accepted norm for individuals' physical sizes to be altered to more accurately comport with their intellectual capacity, society would need to determine where to draw the line. For example, society might find it more justifiable to stunt the growth of a child whose mental capacity will remain similar to an infant's. Society may find it less palatable to stunt the growth of a child whose mental capacity will not exceed that of a twelve year old, since many would perceive this child as having a more fulfilling quality of life. At precisely what level of mental development it would be appropriate to attenuate growth as opposed to allowing full physical development to occur naturally remains unclear. If Ashley's parents and doctors are able to justify keeping her small based upon her mental capacity, it may open the door for abuse of other individuals with varying degrees of mental retardation.

Overall, a court would likely need to conduct a balancing test in order to weigh the potential harms and benefits of Ashley's treatment. In *In re Phillip B.*, the California Appellate Court proposed such a balancing test in considering whether the trial court erroneously denied a petition requesting that a child with Down syndrome be considered a dependent child because the child's parents refused to consent to heart surgery that would prolong the child's life.⁷⁵ The parents refused to consent to the surgery because they thought that it "would be merely life-prolonging rather than life-saving, presenting the possibility that they would be unable to care for [their child] during his later years."⁷⁶ The parents clearly based their decision on their son's mental retardation, as the father testified that he would have consented to the surgery if it had been required for his other sons, all of whom did not have intellectual disabilities.⁷⁷

The court affirmed the trial court's decision and found that the state did not meet the burden of proof necessary to intervene in the parents' medical decision. The court held:

Several factors must be taken into consideration before a state insists upon medical treatment rejected by the parents. The state should examine the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer

serious harm; the evaluation for the treatment by the medical profession; the risks involved in medically treating the child; and the expressed preferences of the child.⁷⁸

In re Guardianship of Phillip addressed a situation where the parents *refused* to consent to medical treatment and the state intervened. In Ashley's case, her parents are attempting to *proceed* with a proposed treatment, and if the state became involved, the state would most likely try to intervene in order to prevent her parents from proceeding with the treatment. A court would still likely conduct a balancing test to ensure that the treatment is in the child's best interest. In a case like Ashley's, it would be difficult for a court to balance the potential harms and benefits because there is a great deal of uncertainty. For example, it is possible that Ashley's doctors are incorrect about her social and physical potential. Given that little is known about the potential mental abilities of those with profound mental retardation, it is entirely possible that Ashley actually has or will have more advanced mental capacities than initially predicted and there is simply a disconnect between her mental capabilities and her ability to express them.

Where there is so much uncertainty, a court may choose to err on the side of caution. For example, even though Ashley may receive benefits from her proposed course of treatment, a court may nonetheless find that the parents should choose the least drastic alternatives possible. If they had chosen less invasive or reversible alternatives instead of the performed invasive and irreversible procedures and sought the court's permission, Ashley's parents likely would have been allowed to proceed with their treatment with the court's authorization. By following this course of action, the parents would have eliminated all questions as to whether the family had potentially violated Washington state law for failing to obtain a court order.

IV. MORAL IMPLICATIONS

The moral implications of allowing Ashley to endure this course of treatment, particularly in light of the bioethical principles of respect for persons, nonmaleficence, and beneficence, must be considered. Laws often reflect what a society deems as moral and immoral; however, the manifestation of moral principles in law often lags behind society's general acceptance of those same moral principles. In this straightforward regard, law is a product of the government's decision to impose moral duties on its citizens.

The principle of respect for persons emphasizes that individuals have the right to make decisions about

what happens to their own bodies, and that society should respect these decisions. In an influential report published by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, the Commission described "respect for persons" as follows:

Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.⁷⁹

Therefore, in evaluating Ashley's treatment from a respect-for-persons perspective, whether the treatment serves to acknowledge and protect Ashley's autonomy must be examined.

Those persons in support of Ashley's treatment may argue that the treatment improves her quality of life by allowing her to be as independent and comfortable as physically possible, and thus acknowledges her autonomy. The lack of menses means one less bodily function that a caregiver must address, meaning less interference for Ashley. The lack of developing breasts may afford Ashley greater comfort while she lies down, sits in her chair, or plays. Without intervention, Ashley likely would have developed large breasts, given her family history, which could have seriously impeded her ability to move as she wished.⁸⁰

In addition to autonomy, the concept of "dignity" is another moral gauge by which Ashley's treatment should be evaluated. Dignity may be considered in one of two ways: as an inherent quality humans possess (i.e., humans are "dignified"); or as a way of describing how we treat others (i.e., we must treat others "with dignity"). Both supporters and critics of Ashley's parents' decision discuss "dignity" in the context of whether the treatment will either deprive or restore

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Ashley's dignity. While Ashley's parents claim that she "will retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development,"⁸¹ critics argue that the treatment violates Ashley's dignity.

Peter Singer, a bioethicist at Princeton University, however, views the concept of dignity somewhat differently. He claims that the concept of human dignity is fundamentally flawed, and, therefore, does not think that Ashley's treatment should be judged solely by whether it violates her dignity.⁸² Singer argues that, while personal dignity is certainly possible, it requires that the subject have a cognitive awareness of dignity.⁸³ Because Ashley does not possess the level of self-awareness necessary to understand the concept of dignity, Singer argues that Ashley should be valued by what she brings to her family, rather than merely valued because she is a human being.⁸⁴ In other words, Ashley's value should be measured not by her nature as a living person, but by what she means to others. Therefore, Singer would likely analyze the question of whether the treatment respects Ashley as a person by not only assessing the ways in which it improves Ashley's quality of life, but also by analyzing how the results of the treatment would improve the lives of her family members.

If Singer's appraisal of personal dignity is correct, then his theory raises several claims that are contrary to sound public policy. For example, under Singer's logic, those who do not want to care for a family member with a seriously diminished mental capacity would be justified in terminating that family member's life, because the family member has little value to the family and little worth to society as an individual. This unseemly proposition would likely horrify much of society.

Even if one does not extend Singer's line of reasoning to such an extreme level, under his theory, a family is left with virtually unfettered authority regarding the life of a family member with diminished mental capacity. This hypothesis allows the family to consider its own interests in addition to those of the family member. For example, Singer's argument would allow Ashley's parents to consider their own convenience in deciding what course of treatment to take for Ashley. If Ashley is valuable only insofar as she improves the life of her family, then based on this premise, the family could determine which medical interventions to order for Ashley based, in part, on their contemplation of how the adjustments would make her care more convenient. Again, such unfettered decision-making authority is inconsistent with public policy.

In addition to autonomy, one can morally gauge an individual's conduct using the principles of non-maleficence and beneficence. Nonmaleficence is the duty not to inflict harm, or risk harm to others, and is typically associated with the Hippocratic Oath that doctors take. Beneficence is the duty to help others by acting in their interest. Ashley's parents and doctors express the belief that they are helping Ashley with the treatment, rather than harming her. There is no direct correlation, however, between the course of treatment and the intended cure. Instead, the benefits of this treatment are more indirect and circuitous. As such, society must consider whether "medical and surgical interventions with significant risk to the individual with intellectual disabilities, [can] ever be justified by indirect benefits to the individual when most [of the] direct benefits accrue to other caregivers such as family members."⁸⁵

If the answer is yes and the benefits to other caregivers are deemed adequate justification for procedures that provide limited benefits to the patient, there is a risk that this validation may open a Pandora's Box to unanticipated and undesirable ramifications. Dick Sobsey, the director of a health ethics center at the University of Alberta, Canada, provides this illustrative comparison of ways in which the indirect-benefit rationale can run afoul: in some countries, families will request that physicians amputate or medically mutilate a child with a disability in order to make the child a more productive beggar.⁸⁶ While this image may be repulsive, the justifications underlying the decision are not that dissimilar to those being advanced by Ashley's family. Caring for a child with a disability can be costly, and a poor family may not have the resources to care for the child at home, despite the family's desire to do so. If the child can beg more productively as a result of his or her exaggerated condition, the family will, in turn, have greater resources to devote to caring for the child.⁸⁷ Alternatively, if a child is not able to leave the home to earn money in this manner, then the family may be forced to leave the child at home, possibly tethered to a piece of furniture to ensure that the child will refrain from hurting himself or others in their absence.⁸⁸

Ashley's case is analogous to the beggar's case in the sense that the parents in both situations would choose a procedure to alter what would otherwise naturally occur for the child. Further, in both cases, the parents' decision also enables the family to provide improved care for the child and ensure that the child will be able to remain with the family. In Ashley's case, her parents argue that the results of the treatment will make it easier for the family to care for her at home,

The principle of respect for persons emphasizes that individuals have the right to make decisions about what happens to their own bodies, and that society should respect these decisions.

allowing Ashley the opportunity to be more involved in family events. In the beggar's case, the parents' supplemented income allows them to afford better medical treatment for the child, and remain with the child during the day while he joins them in begging.

There are also significant differences between Ashley's circumstances and the beggar's case. For example, in the case of the beggars' child, the surgery will dramatically change the child's appearance. In Ashley's case, the surgery will actually *prevent* Ashley's appearance from changing and will ensure that she looks like a six-year-old for the remainder of her life. Furthermore, assuming that the benefits Ashley's parents propose are realized by the treatment, there seems to be a greater correlation between Ashley's procedures and her condition, as opposed to the less apparent link between beggars' child's surgery and his condition. Ashley will arguably obtain some direct benefits from her surgery as she will avoid the discomfort and potential emotional trauma of puberty and may be more physically comfortable with her smaller stature. The beggars' child, however, does not obtain any direct benefit from his surgery. The benefit to the child would be extremely indirect – the surgery may make the child a more productive beggar, allowing the parents to obtain greater income as a result of the child's condition and subsequently use the money to finance the child's care. In this instance, the amputation itself will not directly alleviate any problems associated with the child's condition.

AAIDD identifies other negative consequences associated with the slippery slope of allowing growth attenuation:

With a damning combination of uncertain benefits and unknown risks, growth attenuation as described by Gunther and Diekema is bad medicine, but this practice has even more troubling implications. By extension, if weight ever becomes a difficulty due to age-associated loss of strength for the parents (rather than obesity of the child), then the rationale would suggest that 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.⁸⁹

Essentially, AAIDD questions where the line should be drawn with respect to such therapies. Ashley's parents argue that they are justified in removing Ashley's breasts and uterus because she has no need for them since she will never give birth and will never breastfeed. According to that line of reasoning, the parents would also be justified in amputating Ashley's legs, because Ashley will never be able to walk. Presumably, it is not likely that Ashley's parents would consider ordering such a course of action.

Perhaps Ashley's parents are more at ease requesting Ashley's hysterectomy rather than requesting amputation because society generally accepts hysterectomies, as they are commonly performed, and are elected voluntarily. Amputation, on the other hand, is frequently viewed as a last resort when all other treatment options fail, and very few if any individuals would voluntarily have their limbs amputated. In light of the parents' reasoning for the procedures, forcing Ashley to undergo a hysterectomy, breast bud removal, and growth attenuation therapy is no different from requesting that her limbs be amputated to keep her small.

Given the treatment's "enormous potential for abuse,"⁹⁰ hospital ethics

committees should seriously consider whether to allow such treatment and, if deemed permissible, must ensure that adequate procedural safeguards are in place to protect patients.

V. ANALYSIS

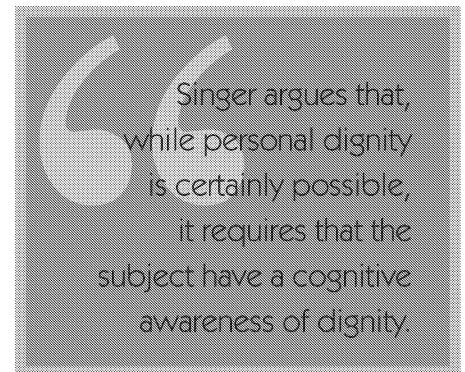
Whether Ashley's parents made the right or wrong decision regarding their daughter's health remains unclear. The fact that their decision strikes some members of society as repulsive does not necessarily mean that courts should prohibit it.⁹¹ Furthermore, it is possible that courts should not take an active involvement in the issue and society should be left to judge whether it is appropriate. As two doctors posit, "[i]f high-dose estrogen treatment is on the right track, the collective community response will bestow general approval on growth attenuation; if not, the criticism may suffice to proscribe this mode of treatment."⁹²

Even though courts traditionally afford strong deference to parents' rights to make medical decisions for their children, a court would likely decide that Ashley's treatment is legally and morally unacceptable. First, a hysterectomy is akin to sterilization—due to the procedure, Ashley will not be able to procreate.

Though the involuntary sterilization of a child with diminished mental capacity is not explicitly prohibited by *Hayes*, Ashley's parents will likely not be able to overcome the legal presumptions against such action. One factor justifying the presumption against

involuntary sterilization is that "the individual is . . . likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy."⁹³ In their blog, Ashley's parents imply that the only way Ashley will become pregnant is if she is abused. Due to her mental condition, she is not likely to engage in sexual activity on her own. Therefore, Ashley's condition might represent an exception to the *Hayes* standard because her mental condition could not allow her to consciously choose to engage in sexual activity.

Since Ashley's treatment affects her ability to procreate, this chosen course of action may also implicate a constitutional issue. The right to procreate is a fundamental right protected by the United States Constitution.⁹⁴ Whether an individual can assert the protection for the right to procreate if he or she is legally incapable of exercising it remains questionable. From a strictly abstract legal perspective, Ashley could be considered sterile; there is no way for her to legally consent to sexual intercourse due to her diminished mental capacity. Therefore, she could not become pregnant without having been abused. One could argue, therefore, that although Ashley has the same "basic civil right" to procreate that other individuals have, she cannot exercise it because she is incapable of ever voluntarily or legally consenting. Her parents then could argue that the hysterectomy would not prevent Ashley from exercising an otherwise exercisable right. Yet, this would raise another slippery slope argument and could run the risk



of becoming over-exclusive in practice. For example, the circumstances of people sentenced to life in prison without the possibility of parole prevent the prisoners from being able to exercise an otherwise exercisable right, namely: the right to procreate. Ashley has the right to procreate, but is prevented from exercising it because of her mental capacity. Prisoners have the right to procreate, but lack the ability to exercise that right. This argument would justify such persons being forcibly sterilized—something the law does not permit.⁹⁵

One might question whether Ashley's parents would be allowed to exercise Ashley's right to procreate on her behalf and would be allowed to artificially inseminate Ashley once she was older so that she could bear a child. Assume that Ashley were an only child, her parents could not have any more children, and she was likely to die fairly young albeit past an appropriate childbearing age. Further, assume that artificially inseminating Ashley would not harm her in any way, and that she would only suffer from the typical pains associated with pregnancy and childbirth. Individuals may be more likely to support this medical procedure than the procedures that have already been performed on Ashley.

This would be especially true if society were to use a substituted judgment analysis to evaluate this hypothetical situation. Under a substituted judgment analysis, supporters of the artificial insemination might argue that, since most women want to become pregnant and have children, it is likely that if Ashley were competent, she would choose to do so as well. The legality of the procedure may turn on whether Ashley, in fact, has a constitutionally protected right to procreate. And, it would further depend on whether, given her legal status as an individual with diminished capacity, she could exercise this right, or others could exercise it for her.

Even if Ashley does not have a constitutionally protected right to procreate so as to prevent her parents from authorizing her involuntary hysterectomy, there may be other less invasive alternatives. Another factor addressed in *Hayes* was whether "all less drastic contraceptive methods . . . have been proved unworkable or inapplicable."⁹⁶ Here, Ashley's parents have not shown why other, less invasive and irreversible contraceptive measures that do not result in sterilization would be inadequate. They profess that the sole purpose of the hysterectomy is to prevent her from experiencing the pains associated with puberty, rather than sterilizing her, which is purely an incidental benefit.

Even if a court declines to extend the reasoning in *Hayes* to Ashley's other procedures, a court would likely err on the side of requiring less invasive measures in an effort to reduce the potential harm to Ashley in the face of such substantial uncertainty. For example, while large breasts may make Ashley uncomfortable in certain chair straps, it is possible that Ashley's parents could find chair straps that are "more suitable for a larger breast size."⁹⁷

Furthermore, while fear of cancer and fibrocystic growths may be reasonable, especially where there is a family history, a court would likely find that this concern is too speculative to require such invasive treatment before it is medically necessary. Given her family history, doctors could simply monitor Ashley's breasts with regular checkups, as they do with other women with a higher risk for developing cancer or fibrocystic growths.

Finally, her parents' argument that large breasts would "sexualize" Ashley, making her more prone to abuse, is unpersuasive; it is equally as likely that "someone might sexually abuse Ashley whether she has breasts or not."⁹⁸ Ashley's parents argue that if she were to be abused, her hysterectomy would prevent her from getting pregnant. Arguably, an abortion in response to a pregnancy would be less invasive to Ashley than a pre-emptive hysterectomy. Because none of these treatments will actually *prevent* or *reduce* the likelihood that Ashley will be abused, a court should find that they are too extreme given the conditions they seek to address.

Should the treatment pass legal muster, it does not mean that the treatment is morally sound. Ashley's case raises significant moral implications. For example, this treatment has significant implications regarding the autonomy of a child with a disability. If, following Singer's logic, humans only have value based on their ability to comprehend their own value or by their affect on others, parents of children who cannot comprehend their own value may be allowed to do a variety of unconscionable things to their children. While Gunther and Diekema advise that "[g]rowth attenuation should be considered only after careful consideration of the risks and benefits to each patient on an individual basis,"⁹⁹ explicit standards and criteria would need to be developed to ensure patient protection. The factor of "convenience" may subconsciously slip into the equation. While such convenience may disguise itself as a benefit in terms of enabling potentially better care, without clear restraints it runs the risk of justifying such behavior as the amputation and mutilation of children to create more productive beggars. While convenience may enable one family to take better care of a child, convenience for another family may result in parental laziness and neglect of the child.

The legality of the procedure may turn on whether Ashley . . . has a constitutionally protected right to procreate.

Even if one agrees with the extrapolation based on Singer's philosophy that, without self awareness, humans have no inherent value except as to what they bring to others, this treatment is still morally questionable because of the substantial uncertainty involved. While Ashley's parents, doctors, and media reports describe Ashley as having the mental capacity of an infant, this description is not entirely accurate. The Supreme Court has held that the "'mental age' concept, irrespective of its intuitive appeal, is problematic in several respects."¹⁰⁰ Relying on an amicus brief submitted by the American Association on Intellectual and Individual Disabilities, the Court found that "[t]he 'mental age' concept may underestimate the life experiences of retarded adults, while it may overestimate the ability of retarded adults to use logic and foresight to solve problems."¹⁰¹

Accordingly, Ashley is not an infant; she is a nine-year-old with severe cognitive disabilities. Ashley appears to be aware of her environment and interacts, in her own way, with her family members.¹⁰² Ashley even interacts with others outside of her family, as she attends a school for special needs children.¹⁰³

Therefore, given how little is known about what Ashley is thinking or feeling, a court may be premature in allowing for such invasive procedures without fully comprehending the potentially profound side effects Ashley's treatment could have on her emotional well-being. The treatment will significantly alter Ashley's appearance vis-à-vis how it would otherwise develop. Sobsey states that "the long-term effects of high-dose estrogen applied to a six-year-old child are likely to result in highly atypical physical appearance that is at least as dramatic as simple amputation. The effects are likely to include extremely short stature, infantilization of long-bone body proportions...acne, and ironically, increased body fat and weight gain."¹⁰⁴ As Ashley matures and sees her classmates around her mature, it is possible that she will notice, and somehow internalize, the difference between her appearance and those of her classmates. In order to respect Ashley's autonomy and act in her best interest, more information is needed as to the potential emotional effects such treatment could have on a child in Ashley's condition.

Courts should also acknowledge that procedures deemed to be legal today could be perceived as shocking to one's conscience tomorrow. This has been especially true of society's historical treatment of persons with disabilities. For example, the eugenic movement of the early 1900s encouraged society to take action to prevent the production of children with mental retardation. "Defective" infants were allowed to die, certain couples were prevented from marrying,

and more horrifically, many persons with mental retardation were sterilized against their will.¹⁰⁵ Perhaps most troubling, the Supreme Court decision in *Buck v. Bell*,¹⁰⁶ which upheld such involuntary sterilization laws, technically remains on the books as good law.

If "Ashley's treatment" becomes a nationally accepted method of treating children with profound mental and physical disabilities, then hospitals must be sure to develop thorough guidelines to ensure that the treatment is performed only when it is, in fact, in the child's best interest. In the event that judicial intervention is necessary, courts should appoint guardians on behalf of children who are possible recipients of the treatment to ensure their moral and legal rights are protected. Treatment should be evaluated on a case-by-case basis by hospital's ethics committees. Further, a court order should be required where the hospital questions the ethical nature of the procedure.

VI. CONCLUSION

Persons with disabilities have a long history of suffering abuse in this country. Whatever irreversible measures are taken in the name of "treatment" must be scrutinized with extreme care. Third parties to this debate, as a whole, have not been privy to or personally involved in the individualized and highly personal decisions that Ashley's parents have grappled with in recent years. The medical community and laypersons, alike, should be wary of endorsing these treatment options without more information and research. While Ashley's parents likely are well-intentioned, good intentions do not always provide for the best interests of the child.

Ashley's parents say that they "did not pursue this treatment with the intention of prolonging Ashley's care at home...[and that they] would never turn the care of Ashley over to strangers even if she had grown tall and heavy."¹⁰⁷ They profess that, even if Ashley weighed 300 pounds, they would find a way to continue caring for her in their home.¹⁰⁸ If that is the case, then one must wonder why the family has insisted on performing the treatment at all. Conceivably, the family could resort to other, less intrusive measures to enable Ashley to be included in more family events.

Even though scientific progress should not stop because of uncertainty, at the least, such uncertainty should lead members of society to pause and reflect. We are not sure what kind of treatment would be in Ashley's best interests. We do not know what she is thinking or feeling. We do, however, know that the kind of treatment her parents have prescribed for Ashley is irreversible and could have profound psychological and physiological side effects. Perhaps science should

“Even though scientific progress should not stop because of uncertainty, at the least, such uncertainty should lead members of society to pause and reflect.”

focus on better understanding the brain and inner-workings of a child with severe cognitive disabilities. Only then will society really be able to know what will be in such a child's best interest.

- 1 See U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTHY PEOPLE 2010: UNDERSTANDING AND IMPROVING HEALTH 6-17 (2d ed. 2000), <http://www.healthypeople.gov/document/pdf/Volume1/06Disability.pdf>.
- 2 See Chris Plauche Johnson, et al., *Helping Families Raise Children with Special Health Care Needs at Home*, 115 PEDIATRICS 507, 507 (2005).
- 3 See Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability*, 160 ARCHIVES PEDIATRICS & ADOLESCENT MED. 1013, 1013 (2006).
- 4 *Id.*
- 5 See The "Ashley Treatment:" Towards a Better Quality of Life for "Pillow Angels" Blog (Mar. 25, 2007), http://ashleytreatment.spaces.live.com/blog/cns!E25811FD0AF7C45C11837.entry?_c=BlogPart (last visited Oct. 30, 2007) [hereinafter Parents' Blog].
- 6 See *id.*
- 7 See *id.*
- 8 See Catharine Paddock, *Public Debates Decision to Keep Disabled Girl's Growth Stunted*, MEDICAL NEWS TODAY, Jan. 5, 2007, available at <http://www.medicalnewstoday.com/healthnews.php?newsid=60268> (last visited Oct. 30, 2007).
- 9 See Parents' Blog, *supra* note 5.
- 10 See Gunther & Diekema, *supra* note 3, at 1014.
- 11 See *id.*
- 12 See *id.*
- 13 See *id.*
- 14 See *id.*
- 15 See Parents' Blog, *supra* note 5.
- 16 See *id.*
- 17 See *id.*
- 18 See *id.*
- 19 See *id.*
- 20 See *id.*
- 21 Gunther & Diekema, *supra* note 3, at 1015.
- 22 See Parents' Blog, *supra* note 5.
- 23 See *id.*
- 24 See *id.*
- 25 See Gunther & Diekema, *supra* note 3, at 1014.
- 26 See *id.*
- 27 See Paddock, *supra* note 8.
- 28 See Gunther & Diekema, *supra* note 3, at 1014.
- 29 See *id.*
- 30 See *id.* at 1014-15.
- 31 See *id.* at 1015.
- 32 See *id.*
- 33 See *Newmark v. Williams/DCPS*, 588 A.2d 1108, 1110 (Del. 1991).
- 34 See *Parham v. J.R.*, 442 U.S. 584 (1979).
- 35 See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205, 233-34 (1972) (holding that "[t]o be sure, the power of the parent, even when linked to a free exercise claim, may be subject to limitation under *Prince* if it appears that parental decisions will jeopardize the health or safety of the child, or have a potential for significant social burdens").
- 36 See e.g., *In re Phillip B.*, 92 Cal.App.3d 796, 802 (1979) (finding that "[s]everal relevant factors must be taken into consideration before a state can insist upon medical treatment rejected by the parents. The state should examine the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation for the treatment by the medical profession; the risks involved in medically treating the child; and the expressed preferences of the child.").
- 37 See DAVID CARLSON & DEBORAH DOREMAN, WASHINGTON PROTECTION & ADVOCACY SYSTEM, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 17 (2007), available at <http://www.disabilityrightswa.org/news-1/ashley-treatment-investigation> (last visited Oct. 17, 2007).
- 38 See *id.*
- 39 See 608 P.2d 635 (Wash. 1980).
- 40 See *id.* at 640.

- 41 See *id.*
- 42 *Id.* at 641.
- 43 See CARLSON & DOREMAN, *supra* at 37.
- 44 See *id.* note 36, at 24.
- 45 See THE BOARD OF DIRECTORS OF THE AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, BOARD POSITION STATEMENT: GROWTH ATTENUATION ISSUE, available at http://www.aaidd.org/Policies/board_positions/growth.shtml (last visited Oct. 17, 2007).
- 46 See 421 N.Y.S.2d 965, 966 (1979).
- 47 See *id.* at 967.
- 48 See *id.*
- 49 *Id.* at 968.
- 50 See Larry Gostin, *A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates*, 11 AMER. J. L. & MED. 31, 58 (1985).
- 51 434 N.E. 2d 601, 604-05 (Mass. 1982).
- 52 *Id.* at 609.
- 53 See Access to Medical Treatment Act, H.R. 2792, 109th Cong. (June 8, 2005), available at <http://www.govtrack.us/congress/billtext.xpd?bill=h109-2792> (last visited Oct. 17, 2007).
- 54 See Access to Medical Treatment Act, *supra* note 53, § 2(13) (defining "patient" as "any individual who seeks medical treatment from a health care practitioner for a disease or health condition").
- 55 See *id.* § 2(12).
- 56 Gunther & Diekema, *supra* note 3, at 1016.
- 57 See *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990). While the Court did not specifically find that there exists a constitutionally protected right to die, it did uphold a state statute allowing for the removal of artificial hydration and nutrition for patients with certain conditions if a high evidentiary standard is met.
- 58 See *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977) (using a substituted judgment analysis in deciding not to approve treatment for a 67-year-old patient with mental retardation suffering from a fatal form of leukemia.).
- 59 See, e.g., *Brophy v. New England Sinai Hospital, Inc.*, 497 N.E.2d 626 (Mass. 1986) (honoring the substituted judgment of a patient in a persistent vegetative state by allowing the removal of the patient's gastrostomy tube); *In re Eichner*, 420 N.E.2d 64 (1981) (relying on a substituted judgment analysis in deciding to remove a patient in a vegetative coma from a respirator).
- 60 Courts seem more hesitant to apply this standard than the substituted judgment standard for patients that were at one time mentally capable. See *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985) (ranking various judgment standards and proposing to apply a best interest analysis only "in the absence of trustworthy evidence, or indeed any evidence at all, that the patient would have declined the treatment . . . [and if] the net burdens of the patient's life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life.").
- 61 See 370 N.E.2d 417, 419-20 (Mass. 1977).
- 62 See *Penry v. Lynaugh*, 492 U.S. 302, 339 (1989) (overruled on other grounds by *Atkins v. Virginia*, 536 U.S. 304 (2002)).
- 63 See *Saikewicz*, 370 N.E. 2d at 420.
- 64 See *id.* at 431.
- 65 See *id.*
- 66 See *id.* at 432.
- 67 See *Woods ex rel Simpson v. Commonwealth*, 142 S.W.3d 24, 34-35 (Ky. 2004) (quoting, 741 P.2d 674, 689, n.23 (Ariz. 1987)).
- 68 *Id.* at 35 (citing the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*, at 134-35 (1983)).
- 69 See Gunther & Diekema, *supra* note 3, at 1016.
- 70 See *id.*
- 71 See *id.*
- 72 See *id.*
- 73 *Id.*
- 74 See *id.*
- 75 92 Cal. App.3d 796 (1979).
- 76 See *In re Guardianship*, 139 Cal. App.3d 407, 418 (1983).
- 77 *Id.* at 418, n.9.
- 78 *Guardianship of Phillip*, 92 Cal. App.3d at 802.

- 79 NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, U.S. DEP'T OF HEALTH AND HUMAN SERVICES, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1979), available at <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.htm> (last visited Oct. 17, 2007).
- 80 See Parents' Blog, *supra* note 5.
- 81 See *id.*
- 82 See Peter Singer, Op-Ed., *A Convenient Truth*, N.Y. TIMES, Jan. 26, 2007, at A21.
- 83 See *id.*
- 84 See *id.*
- 85 See Dick Sobsey, *Growth Attenuation and Indirect-Benefit Rationale*, 10 NEWSLETTER NETWORK ON ETHICS & INTELL. DISABILITY, 1, 2 (Winter 2007).
- 86 See *id.* at 2.
- 87 See *id.*
- 88 See *id.* at 7.
- 89 THE BOARD OF DIRECTORS OF THE AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, *supra* note 45.
- 90 See *id.*
- 91 See Singer, *supra* note 82.
- 92 See Jeffrey P. Brosco & Chris Feudtner, *Growth Attenuation: A Diminutive Solution to a Daunting Problem*, 160 ARCHIVES. PEDIATRICS & ADOLESCENT MED. 1077, 1078 (2006).
- 93 See *In re Guardianship of Hayes*, 608 P.2d at 641.
- 94 See *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).
- 95 See *id.*
- 96 See *In re Guardianship of Hayes*, 608 P.2d at 641.
- 97 See S. Matthew Liao, Julian Savulescu, Mark Sheehan, *The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making*, 37 HASTINGS CENTER REPORT 16, 18 (2007).
- 98 See *id.*
- 99 Gunther & Diekema, *supra* note 3, at 1014 (emphasis added).
- 100 See *Penry*, 492 U.S. 302 at 339 (1989).
- 101 See *id.*
- 102 See Parents' Blog, *supra* note 5.
- 103 See *id.*
- 104 See Sobsey, *supra* note 85, at 7.
- 105 See Brosco & Feudtner, *supra* note 92, at 1078.
- 106 See 274 U.S. 200 (1927).
- 107 See Parents' Blog, *supra* note 5.
- 108 See *id.*